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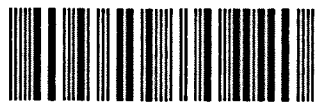
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"It's wonderful becoming a mother...I don't think I am a mum with multiple sclerosis, I'm a mum". The lived experience of mothers with multiple sclerosis in Italy.

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Submitted for the degree of Doctor of Philosophy in the discipline of Health and Social Care, at The Open University, Milton Keynes, England.

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Abstract:

This qualitative study explored the experiences of mothers with multiple sclerosis in Italy, who are an underrepresented group in the academic literature. Few studies have considered the maternal experiences of women with MS, and those that have focus on pregnancy and its impact on the disease, with the wider literature on motherhood and disability concentrating more on women who became mothers when aware of their impairments. This study involved this latter group, but also included women who were diagnosed after becoming mothers.

With phenomenology guiding the methodology, in-depth interviews were conducted (n=16) with women at various stages of MS, with some follow up interviews (n=7). The study explored what factors impacted on the mothering role; the relevance of the timing of diagnosis; any impact of external barriers, and the significance of wider socio-cultural and political influences.

The analysis was conducted using interpretative phenomenological analysis (IPA), from which three overarching themes emerged - *self and identity*, *relationships with others*, and *challenges and support within society*. Self and identity centered on how the participants viewed their role as mothers, with some adjusting their roles in light of their impairments. Relationships concerned the value of friendships and asking for and receiving help from family members. How women discussed their MS with their children, and reactions to this was also discussed, which was particularly relevant regarding the timing of when the women received their diagnosis. Many women faced barriers within society from others' attitudes, including a lack of government support, but also because of physical barriers which affected how they fulfilled their role as mothers. The study findings have implications for practice, which require further investigation. These include recognising the potential of the family in providing empowering support, and the value associated with *being* a mother, rather than solely focusing on *doing* motherhood.

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Chapter 1 - Introduction:

*"È meraviglioso diventare madre... Io non penso sono una mamma con la sclerosi multipla,
sono una mamma!"*

*"It's wonderful becoming a mother...I don't think I am a mum with multiple sclerosis, I'm a
mum".*

(Alessandra).

A national survey conducted in 2009 in Italy found that from the general population aged between 16-64, 15.3% self-declared having an impairment (Academic Network of European Disability experts (ANED), 2011). Despite the number of disabled people living in society in general, and the fact that the number of disabled adults choosing to have children is increasing (Prilleltensky, 2004), my exploration of the literature on disability and parenthood found a general paucity of published empirical studies and an absence of studies which considered the experiences of Italian women.

Chapter 2 will therefore explore the existing literature on disability and parenting, as my overall research aim is to look at the experiences of disabled mothers; but will also discuss the context of carrying out my study in Italy. One significant factor that arises from studies on disability and parenting is the role of professionals in the lives of the women and the availability of appropriate support (Booth & Booth, 1994). However, in Italy, there is an absence of professional involvement in dictating provision of support, due to a general lack of statutory support services and great variation in how any support is delivered (Coulter & Magee, 2003; Bettio et al., 2006; Bettio & Plantenga, 2004; Natali,

2006). There is therefore a tendency to rely on family members to provide support, which largely falls to women (Bettio et al., 2006; Natali, 2006; Naldini & Saraceno, 2008; Miller, 2004). For women who are disabled and who are also mothers, this creates a potential conflict between their roles as both 'carer' and 'cared for'. This absence of statutory support and consequent reliance on intergenerational support therefore guided one of my research questions:

What factors have impacted on the women's roles as mothers since the onset of their MS?

This question relates to whether the women had needed support in maintaining their mothering role and how they felt about this, but also how their perception of being a mother with MS influenced how they maintained their role. Part of the rationale for this question was also in relation to choice and decision making. In Italian society, women do not have equality of access to work or financial independence (Mabilia, 2010), and the socio-political agenda has done little to redress this in recent years (Michaels, 2009; Sundström, 1999). Italian culture also has a strong resonance with the Catholic Church which some suggest continues to reinforce a patriarchal society (Naldini & Saraceno, 2008; Garelli, 2007). In view of these additional socio-cultural factors, a further research question was also defined:

In what ways do wider influences in Italian society, such as the church and the legacy of a government led by Silvio Berlusconi, impact on the lived experiences of disabled women in Italian society?

The literature review also places this question into context, by examining the literature around the socio-cultural and political milieu for women in Italy.

My qualitative study aimed to raise the voices of disabled mothers in Italy, by exploring the lives of women with Multiple Sclerosis (MS) and their roles as mothers. MS is one of the leading causes of disability (Payne & McPherson, 2010; National MS Society, 2010) and the most disabling neurological condition effecting young adults (Payne & McPherson, 2010; Giordano, 2008) in Europe and North America (Giodarno et al., 2010). There are over 2.1 million people throughout the world living with MS (National MS Society, 2010), with 400,000 in Europe (EMSP, 2004). As MS is a condition that is most commonly diagnosed in those aged 20-40 years, with women being two to three times as likely to have the condition than men (MS Society, 2013), it would indicate that a large number of people with MS will be women of childbearing age. There is however a paucity of qualitative studies that consider the maternal experiences of women with MS (Payne & McPherson, 2010), as well as a general scarcity of studies that consider the life role of motherhood for people who are disabled (Farber, 2000). The majority of studies that do consider motherhood issues and MS are focused on pregnancy and its effect on the disease (Twork et al., 2007), rather than empirical studies that consider the lived experience of motherhood for women with MS and the barriers that these women face. The wider literature on motherhood and disability tends to focus on the experiences of women who actively entered motherhood when they were already aware of their impairments, whereas my study has a mix of women who chose to have children when aware of their diagnosis, and those who were diagnosed with MS after becoming mothers. This in part guided one of the research questions which was:

Is the time of diagnosis relevant to the impact of MS on the women's experience of motherhood?

Some of the published studies on the experiences of disabled parents have focused on negative links between parenthood and disability, as they have been approached from a

perspective that views impairment as being the sole source of disability. In contrast, the social model of disability defines disability as being a form of social oppression, rather than a medicalised problem, or an issue of welfare concern. This construction of disability, the social model, is the underpinning paradigm or interpretive stance (Cresswell, 2007) that guided my study and I aimed to avoid adopting a medicalised focus, instead highlighting the socially constructed barriers that impacted on the women's lives. This desire to define the women's disability in terms of social barriers rather than being directly attributed to their impairment guided one of my other research questions, which was:

How do external barriers, such as those related to the environment, society or attitudes, impact on the women's experience of being a disabled mother?

In order to answer these research questions, in-depth interviews were conducted with sixteen women at various stages of MS as defined by the Expanded Disability Status Scale (National MS Society, 2013). Follow up interviews were then conducted with seven of the women, to draw further on issues identified within the first interviews. As the study was conducted in a language in which I am not proficient, native and bilingual Italian speakers were used to assist with the study and their roles and the relationship to the methodology is discussed within chapter 3.

In view of my study exploring lived experience, a phenomenological methodological framework was applied, and underlying feminist and disability literature also guided the study design. In order to actively give a voice to the women, the data was analysed using interpretative phenomenological analysis (IPA), which enables direct quotes from the interviews to substantiate the findings. Discussion around the fundamental methodology and the use of specific methods is within chapter 3, which includes a description of how

the analysis was conducted. Three major themes arose from the analysis. These were *“Self and Identity”, “Relationships with Others”* and *“Challenges and Support within Society”*.

Chapter 4 introduces these superordinate themes and the following chapters, 5, 6 and 7, then break down these superordinate themes into the sub-themes, and demonstrate how the analysis is embedded in the narratives of my participants. The following chapter then discusses these themes in context, by comparing and contrasting them with the existing literature.

At the end of the discussion chapter is a section which considers my final research question which was:

In what ways does this empirical study on the experiences of Italian women with MS contribute to the wider understanding of issues around disability and motherhood?

This section demonstrates how the findings from this study can inform current practice within the setting in which the fieldwork was conducted, but also have broader relevance for professionals in addressing issues of providing appropriate support to other women with MS who are mothers, and other disabled mothers. The section also considers the contribution this study has made towards methodological development in the scope of IPA.

Finally, I conclude with a short chapter summarising the conclusions from the study, which includes a reflective piece on what I as the researcher have learned from undertaking this study.

Chapter 2 - An Overview of the Literature on Disability &

Parenting:

2.1 Introduction.

In order to explore the existing discourse on disability and parenthood, a literature review was conducted to examine the published literature. This appraisal showed a paucity of studies in this field, with the existing literature emerging predominantly from the United Kingdom (UK), the United States of America (USA) and Canada. An interesting point to note in conducting the literature search is that the vast majority of the literature concerns only parenting issues of disabled children, with little reference to disabled people parenting their own children, which has also been noted by other researchers (Olsen & Clarke, 2003). Although welfare reforms in the UK have led to the development of social policies that seek to address the inequalities disabled people face, there remains a lack of both academic research and social policy which specifically concerns parents who are disabled (Prilleltensky, 2003). Within the literature, there appear to be two distinct approaches to the subject of disability and parenting; the first of these is that presented from a medicalised perspective, often conducted by medical or health professionals and aimed at other professionals on how to support disabled parents (see for example Culler et al., 1994) and often suggestive of linking parental disability and negative family outcomes (Kelley et al., 1997; Olsen & Clarke, 2003; Booth & Booth, 1994). The other source of literature is that presented from the views of disabled people themselves, highlighting barriers to disabled people in their parenting role. My research aims to enable the voices of disabled women to be heard, using a social model approach which sources the oppression of disabled people within socially constructed barriers, rather

than their impairments. Hence this chapter focuses on exploring the literature which considers disability as an issue of social oppression.

As the fieldwork for my research was undertaken in Italy, the second element of this review will consider the socio-cultural implications for carer roles in this environment, drawing on the literature around families and disability where it is available. This literature indicates that the social construction of families leads to a strong reliance on face-to-face family contact in Italy (Tomassini et al., 2004), and a more family based model of care than might be expected in the UK (Naldini & Saraceno, 2008). Examination of gendered parenting roles also indicates a more patriarchal system in Italy, with social policy failing to redress the gendered distribution of child care tasks and access to adequate child care (Miller, 2004). This cultural environment therefore represents a very interesting fieldwork context. With both Italy and the UK incorporating European Union directives to implement anti-discriminatory legislation nationally, barriers for disabled parents need to be acknowledged and addressed, to ensure that issues of inequity are accounted for. Furthermore the issue of gender equality will also be relevant to consider. Nonetheless there is evidence that issues around equality have been more proactively addressed in the UK than in Italy, where social and family policy is excessively complex and inadequate, and there remains a lack of welfare support (Naldini & Saraceno, 2008). The literature which discusses these issues of equality in Italy will be considered within the second part of this chapter, considering the cultural and socio political context of both disability and feminist issues within Italian society.

This chapter firstly explores the general literature on disability and parenting, and then explains the reason for exploring the experiences of mothers only. I will then outline the

literature around MS and motherhood, before considering the scope of my fieldwork setting. Within this chapter, literature from the UK is considered as well as that drawn from other countries, in order to enable comparison of the potential influence of disability policy in the two European countries of Italy and the UK, but moreover because within the UK the disability movement has facilitated significant advances in redressing inequalities for disabled people within the socio-political field which Italy could perhaps learn from. Prior to discussing the existing literature, firstly, I will explain how my review was conducted.

2.2 The Search of the Literature.

In identifying relevant literature around parenting and disability, the search terms “parent” and “mother” and their synonyms were used; in combination with the term “disabled” and its synonyms. A number of databases were searched, including AMED (Alternative Medicine), Academic Search Complete, CINAHL, MEDLINE, psycARTICLES, and psycINFO, which are the commonly recognised databases for rehabilitation professionals and those interested in the social sciences. In order to broaden my search, I also utilised the “one stop search” facility of the Open University Library, which searches a cross-disciplinary collection of about forty of the largest and most commonly used databases (Open University). Searches of the Open University library catalogue and the Disabled Parents Network (www.disabledparentsnetwork.org.uk) and other organisations that focus on parenting, such as the Maternity Alliance and Mums Net, were also carried out. Using the above key words, an absence of literature on disability and parenting was found therefore I extended my search to identify research on parenting for specific impairment groups, as evidence by Olsen and Clarke (2003) indicates that the majority of literature on

disabled parenting is in relation to specific impairments. In order to ensure that any literature covering mothering and disability was located, I then broadened the search terms to include terms around specific impairments, such as multiple sclerosis, rheumatoid arthritis, spinal injury. I also limited the search by excluding the term “disabled children”, by applying the Boolean term “NOT” for this wording. This search yielded more results that were accounts of parenting as a disabled person. From these references, I went on to identify a number of further pertinent studies by using the technique of tracing and utilising further literature from articles’ reference lists, what Timmins and McCabe (2005) refer to as the networking method of literature searching. This method aided me in broadening my search.

In order to ensure that no existing work had been conducted in Italy, in exploring the experiences of disabled women on their role as mothers, a WorldCat search was conducted via the OU library. WorldCat holds records of 49 million books and other materials in libraries worldwide. With the aid of Google translate to translate the keywords; a WorldCat search limiting the language to Italian was conducted. The following key words and translations were used: maternita (motherhood), madre (mother), madri (mothers), invalidita (disability), handicap (handicap), la sclerosi multipla (Multiple Sclerosis), genitore/i (parent/s), bambino/i (child/ren). All possible combinations of these terms were used and no Italian language published studies were found that looked at any issues concerning disabled parenting.

As well as the above searches, I also contacted a number of academics from within the field of disability, both English and Italian speaking, but was unable to locate any studies that specifically investigated issues around disabled parenting, or on attitudes to disability

(which was explored to try and locate some more qualitative information on disability). I am therefore reliant on the few quantitative pieces of information on disability that are available, to shed light on the Italian perspectives on disability, which consist predominantly of statistical data. Perhaps the lack of empirical studies on issues around disability is due to the lack of standardised understanding of what constitutes disability in Italy, as a census to establish prevalence of disability, found that different definitions of what exemplifies disability continue to occur (Fondazione Censis, 2010). In terms of the availability of data around disability, Italy still has a tendency to collate information on disease diagnosis, impairment, interventions and outcomes; rather than information linking diagnosis with meaningful health outcomes, such as engagement in social roles (Kostanjsek, 2009), hence the few quantitative studies on disability that were found in this context. The following sections will therefore review the wider literature on disability and parenting. What is highlighted in these studies is the role of professionals in provision of support (Booth & Booth, 1994; Olsen & Clarke, 2003) and the failure to provide appropriate flexible support in a timely and proactive way (Gooding, 2000). The literature also indicates that disabled parents feel the need to demonstrate exemplary skills in parenting, to demonstrate to potentially judgemental professionals their capacity to effectively parent (Grue & Laerum, 2002). This apprehension around professional judgement can lead to disabled parents deciding not to access support they are entitled to, or instead relying on family members, including children, to assist them with support (Gooding, 2000). The literature also suggests that there are a variety of barriers; physical, environmental and attitudinal, that affect disabled parents (Reid et al., 2003). All of these issues which are highlighted in the literature as having influence on the lives of disabled people will be explored in more detail within this chapter. However, to put the

current literature into context I will begin by giving a brief examination of the history of disability and parenting.

2.3 The Historical Background on Disability and Parenting.

Up until the second half of the 20th century, eugenic theorists were largely prominent in influencing society's view of preventing those who were perceived as "defectives" (that is, disabled people) from having children (Olsen & Clarke, 2003; Llewellyn et al., 2010). Within the UK, welfare reforms in the 1940s continued to reinforce society's view of those with impairments being reliant on others to take care of them, and this concept remained relatively unchallenged until a shift in government policy towards "care in the community" emerged in the 1960s and 1970s (Barnes & Mercer, 2004). The establishment and growth of the disabled people's movement, along with the advent of equal opportunities legislation have gone some way in challenging this dominant view in more recent years, but overturning the underlying negativity towards disabled people having families has been a protracted process and disapproving attitudes from both society and professionals have continued to prevail.

The discourse on disabled people being parents is therefore a relatively new phenomenon in the field of social policy and research. However, the topic of disabled people being parents has begun to have more significance, with disabled people both exercising their right to have children and becoming more vociferous in highlighting the barriers they face (Olsen & Clarke, 2003). The source of this discourse has emerged from feminist and disability perspectives with the advent and progression of the feminist and disability movements, with women and disabled people exerting their choices and right to

have children, and the disability rights agenda defining the prerogative to parenthood as a fundamental human right (Llewellyn, 2013). Although there have been some conflicts within these frameworks, with the disability movement not explicitly addressing the issues of women and the feminist movement overlooking disabled women (Morris, 1993b), there is a shared and collective agenda of highlighting oppression and inequality for both of these groups. The construction of the discourse on disability and parenting in the realm of social research has therefore been heavily influenced by both of these groups. However, the majority of this literature has emerged from the USA and UK, where the disability movement and progression of feminism have been in place for some years. This may not necessarily represent the discourse and situation of disability and parenthood in other countries, but nonetheless it provides interesting background context for the purposes of this study. As referred to above, one of the predominant issues arising from the literature on disability and parenting is the role of professionals in the lives of disabled people.

2.4 The Involvement of Professionals.

One particular factor that arose from the literature was the substantial involvement of professionals in the lives of disabled parents and in many countries, it is only relatively recently that disabled people were not subject to open opposition to their right to have children, to the extreme of young disabled women being involuntarily sterilised up until the end of the last century (Olsen & Clarke, 2003), which continues to prevail for many young women with intellectual disabilities (Llewellyn, 2013). For disabled people, their parenting practices are perhaps more deeply scrutinised by health and social care professionals, than for non-disabled parents, both in terms of enabling them to access

support and monitoring their ability to parent (Lloyd, 2001, Llewellyn et al., 2010). Whilst non-disabled people can exercise relative choice in their child rearing practices, disabled people can have their choices restricted, not only because of structural barriers, but also due to a need to demonstrate to professionals and sometimes their own family members, their ability to manage adequately and to demonstrate 'good enough' parenting (Llewellyn, 2013). Booth and Booth (1994) undertook a qualitative study to investigate the experiences of men and women with learning difficulties, who were parents. The study took place in the UK and involved in-depth interviews and considerable telephone and face-to-face follow up contact, in order to adopt a life story approach. What is particularly apparent in their findings is the level of professional involvement in the lives of their participants, which was reflected in other studies on the lives of disabled parents. Booth and Booth (1994) argue that there are no defined criteria for judging parental competence and that the subjective opinions of professionals are used as a basis for decision making on disabled people's right to care for their children.

Many disabled people report the lack of cooperation they receive from professionals, in their search for support in becoming parents (for example Wates & Jade, 1999). From the literature, the lack of skills and recognition of the requirement for further education and training for health professionals working with disabled mothers has also been highlighted (Culler et al., 1994, Tarleton & Ward, 2007). Able Lives, a collation of the responses to a questionnaire sent to female members of the UK Spinal Injuries Association, describes the experience of being a mother with paralysis (Morris, 1989). Although the accounts are distinctive to the particular situation of each mother, they contain a common consensus that independence with motherhood is dependent on the correct and adequate resources being in place (Morris, 1989). When looking at such literature, directly from

disabled people, the powerful role professionals hold was highlighted. This is outlined further below, due to the role that professionals have in decision making around what statutory support disabled people are entitled to receive.

Medical and health professionals therefore have had an important role to play in determining society's approach to disabled people having children, and Booth and Booth (1994) suggest that research done by professionals is given higher status than that which comes from direct accounts of disabled people. The social construction of professional status and role may also influence how professional involvement is viewed in the lives of disabled people, and a national Italian survey found that people viewed the roles of medical professionals in a hierarchy, with doctors having the highest regard of professionals (Coulter & Magee, 2003). This has relevance to my study in terms of how formal support is accessed and perceived and how the role of medics and professionals impact on the lives of my participants.

The socio-economic factors linked to parenting effect issues such as the availability of housing, transport, employment and educational opportunities. These factors are perhaps even more pertinent to disabled people, who are more likely to be unable to access education and employment, which can influence access to appropriate housing and transport. All of these factors are influential in effecting family functioning and dynamics and can impact on how parental competence is judged by professionals (Booth & Booth, 1994). The following section will explore the literature relating to children of disabled parents.

2.5 Children and Disabled Parents.

Whilst some disabled people convey positive experiences of enabling support, the majority of accounts of disabled people identify how a lack of support from formal community resources has resulted in them relying instead on other family members to assist them. The role of children in this assisting role has led many disabled parents to be fearful of accessing formal support services, due to the subsequent judgement of professionals and family members. In the UK there has also been a surge in public interest and subsequent policy development concerning the role of children in providing what society considers to be excessive care and support within the family home (Newman, 2002). “Young carers” have therefore attracted the interest of social welfare and support, in ensuring that they are protected from taking on roles that are disproportionate to their young age. Booth and Booth (1994) suggest that the role of social workers has shifted from being one of family support, to becoming more concerned with child welfare and Newman (2002) suggests that the underlying proposition of young carers’ services is that parents are failing in their duties.

However some studies present a differing view of young carers. For example Blackford’s Canadian study (1999) found disparities between the speculative views of theorists on the experience of growing up with a disabled parent and the real accounts of the children in her study. She interviewed twenty-two children who had a parent with multiple sclerosis. She suggests “...children interact reciprocally with their immediate social world in a manner which transforms themselves, as well as that world” (Blackford, 1999:674). This matches the accounts of many women from Wates and Jade’s (1999) anthology, which indicates that children naturally adapt to their mother’s impairment, through adaptation

of their own behaviour and responses. These two studies suggest that children naturally alter their behaviour to accommodate their parent's impairments and would view this as being the norm to them as a family, rather than being forced into a carer's role suggesting they become a child "in need". The fact that the children are borne into families where a parent is disabled indicates that this is a normal environment for them, whereas for children whose parents become disabled later (which was the case for some of my participants), this natural adaptation may not necessarily come into force.

Grue and Laerum's (2002) study found that, although the majority of parents would think it reasonable to ask children to contribute to household tasks, some parents in their study were reluctant to place any demands on their children to contribute to everyday household chores. This was because their participants were fearful of the perceptions of others seeing them being reliant on the support of their children, rather than seeing it as a normal demand to expect their children to participate. "Children's helping was seen within a discourse of disability and not within a discourse of socialisation" (Grue & Laerum, 2002:679); that is, if the parent were disabled, the children were seen as being their mother's assistant, whereas if the parent were non-disabled, the children were seen as just contributing to everyday family tasks. However, other mothers from Grue and Laerum's (2002) study were pleased with the attributes their children developed through the tasks they assisted with, describing their children as understanding of diversity and thoughtful in their behaviour. When children have been tasked with taking on responsibility for home tasks, sometimes this has been done for the purpose of increasing the child's independent living skills, rather than due to necessity (Prilleltensky, 2004). It appears from the literature then that some disabled people are recognising and promoting the benefits of engaging their children to have increased responsibility within

the home environment, as part of their role within the family. The roles and needs of a family need to be considered as a whole, rather than separating out the needs of the child, in isolation from the family context. Other studies have recognised a limited appreciation of the whole family's needs and the lack of joined up and timely service provision (for example Goodinge 2000; Banks & Pearson, 2004).

UK Government policy has moved towards directing services to ensuring the needs of child carers are met, rather than addressing the underlying issue that disabled parents are not receiving the support that they need to enable them to effectively meet their family's needs. As has been highlighted above, some parents advocate the benefits of their children taking on more responsibility for care and household tasks. Other studies suggest that children of disabled parents naturally adapt to their environment and modify their demands accordingly. However, what is also evident in the literature is that endorsing the role of children in this assisting role can sometimes incur a fear of accessing support services by disabled people, due to the subsequent negative judgement of professionals and family members. This puts additional pressure on disabled women to present themselves as perfect mothers, managing in challenging situations, when support would assist them, for fear of being seen as unable to cope with their children (see for example Thomas, 1997; Kent, 2002). The following section will further explore issues around family support.

2.6 Family Support.

There is evidence that a high level of social support leads to faster recovery from illness and better outcomes in function (see for example Glass et al., 1993; Kwakkel et al., 1996).

However, studies have also found that for some disabled parents, assistance from family members can be overbearing and stifle autonomy as a parent. For example, Ehlers-Flint (2002), undertook a study in California on parenting perceptions and experiences of mothers with intellectual difficulties. She interviewed twenty mothers with mild to moderate cognitive impairments, between the ages of 21 to 43 years. Unlike many other studies, Ehlers-Flint (2002) had a varied ethnic sample within her participants, so different cultural expectations of the role of wider family members may be a relevant factor, although this is not specifically explored in the study. The mothers perceived family support as both supportive, but also interfering (Ehlers-Flint, 2002). Sharing the views of Olsen and Clarke (2003) that there are direct comparisons between the general needs of non-disabled and disabled mothers, Ehlers-Flint (2002) recognises the importance of having a supportive family, but suggests that this support can sometimes undermine the parenting abilities of mothers with cognitive impairments. She suggests that this may contribute to them becoming more socially isolated, due to an over reliance on family members for their social network (Ehlers-Flint, 2002). Generally, mothers in this study reported their support was more helpful than interfering, but over half of the study participants said that their parenting skills had been criticised by their families or other people in their lives. As the participants in this study were women with cognitive impairments, there may be interesting comparisons to make with my study, as my participants largely had physical, rather than cognitive impairments.

Thomas' English based study (1997) found that disabled women feared the judgment of their families, as well as professionals, in supporting their role as mothers. For the two mothers in Thomas's (1997) study who had had their children removed from their care, this was due to the actions of their family members, rather than professionals. This study

found that family members were often overpowering in their attempts to offer support to the disabled mother in managing their children's needs (Thomas, 1997). This may reflect the tendency of society to view disabled people as passive recipients, rather than providers of care. Families of disabled people who become parents themselves, may therefore feel socially obligated to provide on-going care for their grown up disabled children in their parenting role, rather than facilitating their independence by lobbying statutory services to provide appropriate support.

A study undertaken by Payne and McPherson (2010) in New Zealand, on the experience of women with MS becoming mothers, found that seven out of the nine participants remarked on the crucial contribution of their husband's support. However, examination of gendered parenting roles indicates a more patriarchal system in Italy, compared to America, Australia, France and Denmark; with studies on support within the family home recurrently suggesting that Italian men contribute very little to household tasks (Craig & Mullan, 2010). How women were supported by their husbands with childcare tasks and the role that husbands took in supporting my participants were therefore crucial areas to investigate in my study, particularly with regard to gendered role expectations and any changes in role.

Payne and McPherson's (2010) study participants also commented on the invaluable support from their own mothers in assisting with child care tasks. The literature suggests that in Italy, there are already existing expectations that grandmothers are engaged in providing childcare support (Sarti, 2010), but this may be more reflective of the absence of formal childcare provision. In Italy, the social construction of families is exemplified by

the strong reliance on face-to-face family contact and a more family based model of care (Miller, 2004). The literature shows that there remain cultural expectations from family members to provide care and support to other family members in time of need and that this responsibility largely falls to women (Bettio et al., 2006; Natali, 2006; Naldini & Saraceno, 2008). Therefore, for many women in Italy, the expectation will be that they adopt the role of informal carer, providing support to family members who need it. Nevertheless, intergenerational support is not exclusive to Italy, as greater numbers of middle-aged adults in other socio-cultural settings now have to balance the needs of their own children alongside assisting aging parents (Riley & Bowen, 2005). However, exploring the experiences of disabled women, who may need to be 'cared for' as well as have a role of 'caring for', is appropriate to consider within my study analysis, especially within a culture in which family ties are so strong. Furthermore it is suggested that Italian culture is equally if not more responsible for inequalities in implementing independent living for disabled people in Italian society (ANED, 2011), so the cultural expectations around independence and support are vital to consider.

Although the family remains an important source of informal support throughout Europe, welfare policies assist or supplement this in different ways, which impacts on social and economic outcomes (Bettio & Plantenga, 2004). It is suggested that Italian families supplement underdeveloped welfare services by providing social support within the family (Natali, 2006) and that there is little incentive for the state to redress this (De Rose et al., 2008). A number of studies also suggest intergenerational support is stronger in Italy than within other European countries (Zontini, 2006; Glaser & Tomassini, 2000). Strong relationships between parents and adult children, subsequent geographical residential proximity of parents and their married children, along with regular face-to-

face and/or telephone contact continues to exemplify Italian families (Zontini, 2006). Glaser and Tomassini (2000) quote several studies that demonstrate the increased frequency of contact between adult children and their parents in Italy, compared to Britain, which they say reflects the cultural norms in these two countries (Glaser & Tomassini, 2000). Their study concluded that intergenerational proximity in Britain was more likely linked to the health needs of older parents, whereas in Italy, the proximity was related more to cultural expectations, regardless of parental need, although reliance on continued parental financial support also impacted on this proximity (Glaser & Tomassini, 2000). Sundström (1999) also recognises the strength of the economic role in Italian families and the unpaid role of family members in contributing to family welfare. Geographical proximity of the families of my participants was therefore identified as a pertinent factor to be investigated in my study.

It is recognised that different European countries vary greatly in how they rely on informal care, which is influenced by cultural and political situations (Bettio & Plantenga, 2004). Drawing on data from the European Community Household Panel, which they suggest indicates the level of informal care provision, Bettio and Plantenga (2004) examined care provision across fourteen European countries, although they considered only care provision to children and older people. Similarly, when I searched the literature for studies on the provision of support in Italy, I could locate only studies that considered the remit of formal support services for the elderly and children, with a lack of studies that considered statutory support to adult disabled people. In this particular study, Bettio and Plantenga found that there was heavy reliance on informal care in Italy, Greece and Spain, as they anticipated, due to the strong family unity of Mediterranean countries.

They also unexpectedly found that the UK had a high reliance on informal care, though on further exploration, when considering care provided by adults over the age of 50, Italy was the highest country dependent on informal care, with the UK coming fourth from bottom. This suggests a greater reliance on intergenerational support in Italy, which matches the expectation of strong family cohesion in this country (Bettio & Plantenga, 2004). This is relevant to my study, in terms of how my participants perceived the intergenerational support they received.

Bettio and Plantenga (2004) conclude that southern European countries, such as Italy, rely heavily on family care due to the lack of public provision of care for children and the elderly. Therefore they are less orientated towards equality for women, with reinforced gender specific roles because of disincentives in the tax systems for women to seek paid employment, thereby corroborating the sexism implicit in social policy in terms of discouraging women to undertake paid work. The impact of this for disabled women in the role of care provider is relevant to consider in Italy then, due to the implicit expectations that women will be providers of intergenerational care that is, to both children and older relatives. Furthermore, in countries like Italy, where there are strong informal intergenerational support systems in place and little prospect of change without significant political involvement (De Rose et al., 2008), this continues to perpetuate perceptions that external support services are inadequate substitutes for family care (Bettio & Plantenga, 2004). This is particularly relevant to my study in terms of considering how disabled women perceived the adequacy of informal and formal support they received, as this may have influenced take up of any externally available support services that might exist.

2.7 Friends and Social Support.

There is little published literature that considers whether or not disabled women rely on the support of friends to assist them with parenting. The studies that do highlight support from friends, referred to disabled women speaking of the moral support and practical tips they had from fellow disabled mothers, rather than from non-disabled friends. It is unclear whether this lack of literature is due to the support of friends being encompassed in the research on social support in general, with friends remaining unclassified as a specific source of support. As a mother, an amount of social contact is gained through one's children; for example meeting other parents at parent and toddler groups, outside the school gates, at play dates and such like. Investigating how non-disabled people support disabled friends was therefore relevant to my study, in terms of social support, as it has been suggested that when a mother is disabled, she becomes more socially isolated (Ehlers-Flint, 2002). The opinions of disabled women on the appropriateness of utilising support from friends and family formed a major part of my research study. This element was therefore included within my data collection; to examine what support and social interaction disabled mothers had, both with disabled and non-disabled mothers. However, it is important to also take into account the role of formal support. With reference to provision of support, Olsen and Clarke suggest:

“For disabled parents and their families to be provided with the holistic, flexible and responsive support essential for enabling successful parenting, it is important that formal support is offered in a way that promotes, underpins and enables existing family and friendship relationships” (2003:57).

This suggests that there is a need for formal support to adapt to the needs of disabled people and to embrace their relationships with friends and family. However, it is evident from the literature that when disabled parents need support, many rely on family members to provide assistance, rather than utilise formal support. The following section will examine the published evidence behind this.

2.8 Availability of Formal Support.

Both statutory and voluntary services provide support to disabled parents, including social services, health and voluntary providers, but it has been evidenced within the UK that there is a lack of cohesion between services and varying levels of support between different geographical locations (Goodinge, 2000). A UK study carried out with parents with intellectual disabilities also highlighted the value of co-ordinated professional support with parenting issues (Tarleton & Ward, 2007). Within the UK it also appears that disabled parents are not identified as being a specific group of service users and therefore in terms of accessing services, they fall between two groups; that of adult services, focusing on personal care needs; and children's services, focusing on the child's welfare (Booth & Booth, 1994), though it should not be assumed that all disabled parents will need access to formal support services to assist them in their parenting role (Olsen & Clarke, 2003).

Despite the recent celebrations of 150 years of a combined republic in Italy, there remain significant regional differences in state support, with the north commonly being better provided for than the south and a general underdevelopment of welfare services in Italy compared to other EU countries (Natali, 2006). There is much variation in how statutory

support is funded and delivered across the different regions of Italy (Coulter & Magee, 2003; Bettio et al., 2006) and even variation between hospitals in the same region (Uccelli et al., 2002). Moreover access to general public provision of care in Italy is said to be woefully inadequate both in terms of availability and flexibility (Bettio et al., 2006), and it has been argued that Italian families have a strong role to play in providing informal care (Natali, 2006) to supplement state provision. In spite of this, studies that consider national differences in care provision are scarce, as is consideration of the relationship between the state and the family (Bettio & Plantenga, 2004). Although in the UK it is suggested that services for disabled parents have some inadequacies (Goodinge, 2000), there is a reasonably comprehensive standardised provision of support for disabled people; in that all social care providers are legislated to provide certain standards of support to disabled people, which are monitored via statute through the Care Quality Commission. In Italy, with the vast regional variation, both in service provision and definitions of disability (Francescutti et al., 2009), dependence on a consistency of minimum standards cannot be guaranteed, which may impact on the expectations of disabled people. An Italian study conducted to investigate the preferences of decision making in people with MS (Giordano et al., 2008), found an overwhelming tendency towards a passive or collaborative role, in contrast to the more active participation in decision making reported in a German study (Hessen et al., 2004). Giordano et al (2008) suggest that this more passive participation is due to cultural differences and the protracted take up by Italy of WHO recommendations on patient and citizen empowerment, compared to that of Germany. This relatively passive approach to decision making is relevant to my study, in terms of how proactive my participants felt able to be, possibly due to entrenched cultural factors, in seeking appropriate assistance.

Olsen and Clarke's (2003) UK study, funded by the Department of Health, looked at the role of formal and informal support for disabled parents. This study revealed that "Several parents had requested help with looking after their children; the services, however, were unwilling to recognise that parenting was a valid support need..." (Olsen & Clarke, 2003:41). It also appears that community support from adult services is solely directed at ensuring personal care needs are met, rather than taking a broader view of the individual support needs of disabled parents. For example, a UK government report recognised that adult community care services focused on the personal care needs of the individual, rather than undertaking a holistic assessment of the individual in the context of their family (Goodinge, 2000). As one participant from their review commented: "I only received services for myself and not for my child which left me dependent on my parents for that support" (Goodinge, 2000:19). Whilst reliance on family support has been discussed above, these studies are relevant as they reflect the failure of the structure of the systems professionals work within, to recognise the context of providing services for disabled people to meet their holistic needs.

Regulation in the field of social services was not implemented in Italy until the end of 2000 and is said to be excessively complex (Naldini & Saraceno, 2008). This regulation was then undermined by subsequent constitutional reform which delegated responsibility for social services and assistance from the state, to the regions of Italy (Naldini & Saraceno, 2008). Therefore due to the autonomous initiatives introduced in some regions (Naldini & Saraceno, 2008) and the absence of national direction, it is likely that those responsible for decision making around welfare provision in Italy lack the necessary skills and knowledge to effectively distribute resources, unless they are familiar with local resources and legislation.

It has been suggested that informal support occurs on a continuum, with support adapting and changing on a flexible basis, dependent on the requirements of the mother and the stage of her life (Prilleltensky, 2003). However, it appears that, at least within UK provision, formal support does not encompass this flexibility. A Department of Health funded study, which inspected eight local authorities to evaluate their role in supporting disabled parents in their parenting role, found a number of concerns around services being unable to adapt in a timely way, when the needs or circumstances of disabled parents changed, which staff attributed to a lack of resources (Goodinge, 2000).

It has also been argued that disabled people are unaware of how to access services (Olsen & Clarke, 2003), and although professionals who work with disabled people should be fully aware and able to promote available services, research has shown that professionals are not always fully equipped with the skills and knowledge to do this. For example Thomas's (1997) study found many participants recounted that, though well intentioned, professionals lacked the information or expertise required to effectively assist them. Her participants described examples of how, in attempts to provide support, health care professionals had provided inappropriate assistance, without consulting the disabled mother. Many participants found out about aids and equipment to assist with parenting tasks by chance, or through networking with other disabled mothers (Thomas, 1997).

Reid and colleagues (2003) conducted a qualitative study of eleven mothers who were full time wheelchair users. They too found that information on adapted equipment for disabled mothers was difficult to find and mothers either had to be intuitive in finding alternatives, or had to cope with inadequate arrangements. In considering formal support, it is evident that there is a lack of appropriate resources, whether that is professional knowledge, or practical support, that appropriately facilitates the autonomy of disabled people who are parents. Parenting as a specific issue of support has been

overlooked as an area of need and continues to be inadequately considered in social policy and research.

The availability and therefore provision of support for disabled parents is dependent on public spending, so relies on the government allocating appropriate resources to health and social care. It has been suggested that the financial support the government allocates to supporting disabled parents is dependent on the level of importance given to disabled parents as a distinct group (Prilleltensky, 2003). Indeed Prilleltensky (2003), drawing on the work of Wates (1997) suggests that it is the lack of resources, despite professionals' recognition that the services are required, that compromises health and social care workers. Alongside the absence of resources, it has also been identified that there is a lack of knowledge on the part of health care professionals on the specific needs of disabled women during pregnancy, birth and post-partum care (Lipson & Rogers, 2000). However, others have suggested that it is professional opinion, rather than what parents say they need, that influences provision of support (Llewellyn, 1995 in Kelly et al., 1997). Perhaps the combination of a poverty of resources, a lack of understanding of the real issues and lack of flexibility by service providers is what hampers access to services (Prilleltensky, 2003).

As the decision makers in the allocation of services, professionals thereby influence the availability of resources (Olsen & Clarke, 2003) and the consequent reliance of disabled people on family support to augment formal support services where they are lacking.

Although research suggests informal support plays an important part in the care of disabled parents, given the wide variation in availability of formal care in Italy, women's

experiences need to be examined within the context of their daily lives, to ascertain how formal and informal support interact.

2.9 Attitudes of Society.

The views of professional decision makers thereby have a huge influence on enabling disabled people to maintain their autonomy as parents. There are some examples of positive support offered to disabled parents from professionals, such as a minority of accounts in Wates and Jade's anthology (1999). These positive accounts are far outweighed in the literature by a plethora of examples of the negative attitudes and at times, blatant discrimination towards disabled people in their role as mothers (see for example Wates & Jade, 1999).

Parenting is a demanding job, requiring physical and emotional energy and many of the challenges of parenting apply equally to both disabled and non-disabled people (Olsen & Clarke, 2003). However for disabled parents, their ability to fully participate in their children's lives outside the home is often compromised (Kersten et al., 2002; Blackford, 1999; Reid et al., 2003) not by their impairment, but due to other factors such as insufficient support, inaccessible housing, transport and recreational facilities (Blackford, 1999; Reid et al., 2003), all of which are issues that are professionally governed. A Canadian study of mothers who were wheelchair users, found that their ability to participate in their children's lives was to some extent limited by their physical impairments, but moreover was constrained by the inaccessibility of housing and the social environment (Reid et al., 2003). Studies such as these reflect that challenges for disabled parents are due to societal and environmental barriers, rather than being

directly related to their impairments. The women in Reid et al's study were proactive in gaining resources and tackling barriers that they faced, enabling them to maintain as much control as possible over their lives (Reid et al., 2003). My study considers both societal and environmental barriers and the varying effect of these on the lives of disabled mothers. These barriers are also considered in relation to the women's level of impairment, to explore whether such barriers are more or less significant for the women with more progressed MS.

As indicated earlier, the majority of the literature on disability and parenting has been approached from a clinical, scientific viewpoint, borne from the subjective opinions of professionals on negative associations for disabled people as parents. In contrast, the literature arising from a feminist and disability rights perspective provides a different standpoint, that of the lived experience of disabled parents and the barriers they face. For example Morris's (1989) UK study reported on the frustration and sadness mothers felt, at the difficulties they encountered in order to be fully involved in their children's lives. However, rather than being attributed to their impairment, these women perceived that it was the physical and attitudinal barriers that society presented them with that prevented them from full inclusion in their children's lives (Morris, 1989). Thomas' English (1997) study, which sought the views of seventeen disabled women who were either already parents, or who were considering parenthood, recognised attitudinal barriers presented by professionals and family members in judging the parenting skills of disabled people. The study found that women were apprehensive about being or becoming mothers, but only in part due to worries about the limitations caused by their impairment. Their concerns were due more to "the prejudicial attitudes of others and the failure to provide appropriate assistance to disabled parents on their own terms"

(Thomas, 1997:636). Negative attitudes of professionals and family members have also been recognised by other studies (see Llewellyn et al, 2010). There is then some evidence to suggest that professionals and sometimes family members can be unsupportive and display negative attitudes and present barriers, rather than empower and facilitate autonomy in disabled people being parents.

A piece of Canadian research (Prilleltensky, 2003) identified some good practice examples of where formal support from personal assistants was given. In these, the mothers engaged assistants who facilitated them in parenting their children, what one mother termed “parent-directed child care assistance” (Prilleltensky, 2003:40). This type of support enables the mother to remain in charge, with the assistant working under the mother’s direction, enabling her autonomy with her child, rather than taking her authority with her child away. However, Prilleltensky (2003) acknowledges that support of this quality is the exception, rather than the rule. Prilleltensky (2003) also recognises the fact that both of these mothers who had this assistance had to lobby for support workers of this kind and provide training and support for their workers. What this study particularly highlights in the context of my research is the different approaches to service provision and expectations of service users in different countries. My study focuses on service provision for disabled mothers in Italy and their expectations and opinion on the appropriateness of these, which will be compared to the existing literature around satisfaction with formal support services.

The researched experience of disabled parents demonstrates how the professional role often takes a paternalistic approach, seeking to ensure the well-being of children of disabled parents, rather than being a source of facilitative support. This not only

reinforces the discriminatory attitudes of society in seeing disabled people as being unable to fulfil the usual roles of being parents, it also adds to the pressure to demonstrate exemplary standards in parenting, which are beyond the expectations of all. Farber (2000) suggests that comparing to an “illusive ideal” (pp.267) of the perfect mother occurs with all mothers, but is particularly poignant for mothers who are also adjusting to the impact of disability. Kent (2002) too recognises that many new mothers feel under pressure to depict themselves as being good mothers, but in her account of being blind and becoming a mother, Kent (2002) felt her performance as a mother was judged more critically in view of her impairment. She describes accounts from other blind mothers from the USA of the extra scrutiny and suspicion they felt they were subject to as mothers, in view of their blindness alone, rather than due to any deficits in their parenting (Kent, 2002).

Although a recent study of parents with intellectual disabilities recognises the benefit of empowering professional support (Tarleton & Ward, 2007), there remains a pervasive fear amongst many disabled parents of needing to prove the adequacy of their skills as a parent. Grue and Laerum (2002) carried out a study of physically disabled mothers, within the age group 28-49. Their study was somewhat larger than many qualitative studies of disabled mothers as a specific group, conducting semi-structured interviews with thirty women, in Norway. They too found many of the women in their study felt the need to demonstrate excellent skills as a mother, and to demonstrate their competence to others, what they describe as being “supermum” (Grue & Laerum, 2002:677). This was due to mothers feeling the need to perform to the perceived expectations of society’s definition of a good mother, for fear of being seen as being inadequate mothers. Ultimately, this was because of concerns about having their children removed (Grue & Laerum, 2002). For

some, asking for help was used as evidence to substantiate inadequate parenting skills (Grue & Laerum, 2002). Grue and Laerum argue that there has been a neglect of disabled parents as a distinct group in the Norwegian social and political context and conclude that for disabled women, their parenthood is rooted in a discourse of disability, rather than one of motherhood (2002).

2.10 The Focus on Mothers.

The focus of my study is the consideration of the views of disabled mothers, thereby excluding fathers from the data collection and analysis. It is recognised that mothers dominate the literature on parenting, thereby marginalising the role of fathers (Olsen & Clarke, 2003). However my study investigated the role of mothers only, as it was also concerned with the influence of the gendered role of parenting and the suggestion that the combination of being disabled, alongside being a woman leads to two fold oppression; oppression as a consequence of being disabled and oppression as a consequence of being a woman (Reid et al., 2003). Investigating the social construction of motherhood and of disability in Italy, alongside issues of gendered role expectations gives an insight into issues of oppression within a different cultural and social context, and it has also been suggested that gender specific social roles impact on life experience (Stone, 2005). However, in examining the literature, some studies have considered disabled parents, rather than solely focusing on mothers, hence the reason why these have been considered above. Some specific studies that considered mothering and MS were also found, which will now be reviewed.

2.10.1 Women's Experiences with Multiple Sclerosis.

As highlighted in the introduction, MS is a condition that is most commonly diagnosed in those aged 20-40 years, with women much more likely to be affected than men (MS Society, 2013). However, there are few qualitative studies that consider the maternal experiences of women with MS (Payne & McPherson, 2010), and those that do so tend to focus on pregnancy and its impact on the disease (Twork et al., 2007). Like some other researchers, it remains my assertion that further research that investigates quality of life matters for mothers with MS is still needed (Twork et al., 2007). There are a small number of studies conducted in America that take account of the experiences of mothers with MS in relation to particular aspects of impairment. For example studies that focus on pain and fatigue (Parker White et al., 2009a & 2009b); or postpartum emotional distress (Gulick & Kim, 2004). Other publications exist (such as McCue, 1995) which serve as advice and information documents for people with MS, but are not based on empirical studies. I also found published studies that considered the impact of parenting with MS that were focused on the experiences of the children. However, many of these studies focused on the negative links, rather than recognising the barriers impacting on these relationships. The studies identified mainly come from the USA and Canada, which is significant as a common theme arising from the findings of the above studies is women's insights into how they viewed themselves in comparison to their perception of an 'ideal mother'. As ideologies of motherhood may differ depending on the social context, investigating the experiences of disabled mothers within Italy brings a new perspective on how disabled mothers compare their role to that of their perceived expectations of the very culturally specific idealised role of mother.

Another significant factor is that some of the above studies, such as those of Payne and McPherson (2010) and McNary (1999), concerned only women who were already living with MS when they were making decisions around motherhood. Other studies (indeed the majority), were not explicit about whether the women already had MS when they chose to have children, or were unable to distinguish this via their data collection tools (Twork et al., 2007). My study is novel in that it included both women who actively decided to embark on motherhood, with the knowledge of having MS, as well as women who already had children when their MS was diagnosed.

It has been suggested that “when a parent becomes disabled after the birth of one or more children, the family may undergo almost unbearable stress” (Meadow-Orlans, 2002:276). McCue (1995) suggests that if the parent is struggling to manage the actuality of having MS, then children will also struggle and fail to adapt. Due to the unpredictable nature of MS, continual adaptation is needed and there has been little research into how people adapt from an occupational perspective (Cahill et al., 2010), that is, how people might modify their life roles. However, it is recognised that adjustment is not a straightforward linear process (Reynolds & Prior, 2003). When my participants became aware of their diagnosis and how it impacted on their decision making and feelings about their role as a mother have been taken into account in my data analysis.

One study that considered the experience of a woman with MS, which takes account of her role as a mother, is a qualitative case study that used existential phenomenological analysis to explore the data (Finlay, 2003). Through narrative discourse, Finlay unveiled that initially the woman operated as two selves, a woman with MS, who raged and despaired at her diagnosis; and a woman who chose to prioritise her role as mother,

giving up her job and career, to focus her energy into ensuring the lives of her children were as unaffected as possible by her impairments. The study focuses on the first year of the woman's life following her diagnosis, rather than being a study specifically looking at the role of motherhood, but what is particularly pertinent is the woman's ability to keep her diagnosis and impairments hidden from her family, due to the lack of externally evident signs of any impairment. This option to hide disability by women with MS is also highlighted in some of the above studies. The implication is that as there are negative links between being a disabled person and being a mother, not disclosing a disability may avoid facing the adverse aspects of society judging women who are disabled mothers. By recruiting women at different stages of severity of MS, my study has captured the experiences of women in similar situations to the woman in Finlay's case study; those whose impairments could be hidden from the external world; but also those whose MS was more progressed and had evident impairments. This has enabled me to explore the different dimensions of impairment; to evaluate perceptions of barriers on women's ability to participate in their children's lives and whether their impairment level related to how women viewed their experiences as mothers. I was also able to explore how women viewed they were perceived by others within society and whether hidden or more physically evident disability engendered different feelings and responses, both from society, but moreover from the women themselves.

My study conceptualises disability from a social model perspective; defining disability as a form of social oppression, viewing society as disabling people on account of their impairment, rather than disability being inextricably linked to impairment. Therefore, whilst the findings of my research are related to the reported experiences of women with MS, they also have resonance for a range of mothers with impairments. The barriers that

disabled women with MS face have wider implications for others who are also defined as being disabled. Environmental barriers that restricted women who are wheelchair users in accessing buildings for example, will be equally applicable to other women who are wheelchair users, whatever their impairment. For women who face oppressive attitudes from others to them being parents, on account of their impairments, there may be applicability to other women who are stigmatised due to their impairments. Likewise for those who have 'hidden' impairments, such as pain, fatigue or cognitive difficulties; issues that were relevant for women with MS as mothers, are also relevant to other women with hidden impairments. So whilst my study focuses on the experiences of mothers with MS and, as a qualitative study, should not be generalised beyond this, my findings do have some relevance to a broader range of women with impairments who are mothers.

In considering motherhood, it is also important to recognise that culture and society influence perceptions of motherhood. When searching the literature it became evident that there were no studies that focused on the experiences of mothers with MS in Italy, with the cultural and social factors around mothering that exist in this environment.

"[N]eeds reflect the cultural context and expectations of the subject [so] it is likely that significant different needs will be identified in different countries for cultural reasons, irrespective of the degree of impairment or dependency of the people with multiple sclerosis." (Kersten et al., 2000:43). The following sections will therefore consider the cultural context of Italy.

2.11 The Socio-cultural Context of My Study.

Not only does my study enable an insight into support for disabled people in a different culture to the UK, it also facilitates an understanding of pertinent issues for Italian women as disabled people, and the impact of social policy in a country where women continue to be subject to a degree of social oppression. The vast majority of literature concerning disability and women's rights has arisen from the USA, Canada and the UK. My research therefore adds to the discourse on disability and parenting, by investigating the experiences of disabled mothers from a European context, and reporting on the direct views of disabled women in Italy. I will now consider some of the wider global literature on disability policy, in order to compare the current status of disability policy and rights in Italy within the European framework, to that of the UK.

2.11.1 The Construction of Disability Policy in Italy.

Since the 1960s there have been many debates around definitions of disability, handicap and illness, and attempts to provide an acceptable conceptual framework (Oliver, 1996). These debates have influenced the revision of the World Health Organisation international classification on disability, impairment and illness (now known as the International Classification of Functioning, Disability and Health, the ICF) and the terminology used within this classification (Oliver, 1996). Despite subsequent revisions of this classification, the ICF continues to have its critics, not least due to the fact that it retains the necessity to give an "in-depth classification (of) individual characteristics" (Hurst, 2000:1084), which reinforces the individualisation of disability, rather than placing the source of disability within its social and political context. Disabled people have argued that the WHO definitions have been a barrier to presenting disability as a rights issue

(Hurst, 2000), allowing the continuation of an individualised “medical model” approach to disability, rather than that of a “social model” which attributes the source of disability to society and the barriers that it presents to people with impairments.

It is essential to recognise that the debates around the conceptualisation and experience of disability for individuals are not simply linguistic arguments, but have arisen directly from people’s first hand experiences, and are inherently related to policy developments nationally and internationally. It is also significant to note that both Italy and the UK are member states of the European Union and it has been suggested that common social policy across the EU states will be inevitable (Rutkauskiene, 2010), though the global economic crisis and austerity measures may now challenge this proposal. Priestley (2007) undertook a review of disability policy from a European perspective, looking at the changes in discourse from the inception of European disability policy in the mid-1970s to the date of his review. Although disability issues were included in European policy recommendations from the early days, a wider social analysis of disability was not apparent until the mid-1980s, alongside the emergent influence of the international disabled person’s movement (Priestley, 2007). Throughout the latter part of the 1990s and the 2000s, the disability rights agenda gathered momentum and the current European Union Action Plan (2006-2015) is based on principles of “human rights, non-discrimination, equal opportunities, full citizenship and the participation of disabled people” (Priestley, 2007:68). These relatively recent changes to disability policy at the European level have evolved into a more enlightened establishment of policy, integrating social protection policy with an equal rights and anti-discrimination agenda (Waldschmidt, 2009).

Prior to a defining moment in anti-discrimination law, initiated by an EU Directive in 2000, the majority of member states did not have anti-discrimination laws with regards to disability (Bell, 2008). The UK took the opportunity to instigate a debate on equality as a general issue, concluding in the establishment of the Commission for Equality and Human Rights (Bell, 2008) and the passing of the 2006 Equality Act (Spencer, 2008), now superseded by the Equality Act 2010. Italy instead chose to define disability law within their pre-existing social welfare legislation, which is more in keeping with the medical model definition of disability (Bell, 2008), placing equality issues for disabled people within a model of 'need' rather than a model of 'rights'. How disability is defined is a key element influencing national policy (Bell, 2008) and an Italian national report acknowledges the great disparity in disability policy between the different regions of Italy (Micangeli et al., 2009). Although part of the European Union, Italy has been slow to take on board initiatives to improve equality and the rights of disabled people (Bell, 2008; Boeri & Ferrera, 2001) and a report concerning the implementation of policies supporting independent living for disabled people states that the first two pieces of legislation that referenced independent living for disabled people were "literally neglected and ignored by regional government" (ANED, 2009:4).

Within the UK additions and modifications to the legislation and service provision for disabled people have been strongly influenced by the Disabled People's Movement. These changes have included altering the way in which disability is perceived from an individualised medical model approach to disability, portraying disability as a 'personal tragedy', to a social model of disability which attributes the source of disability to the barriers that society presents to people who have impairments (Barnes & Mercer, 1996). Although the UK system of welfare support may not be perfect, it is well established and

to date has been relatively consistent in its form of delivery. There are signs within UK welfare policy that disability is being addressed as an equality and rights issue, rather than within a social welfare framework, although the current economic climate may challenge this progression. However, this move from seeing disability as a rights rather than a welfare issue, has not yet translated into the discourse on disability and parenting, and acceptance of this model in general terminology in Italy is questionable. Whilst it is said that disability policy “aims at guaranteeing equal opportunities, participation and inclusion for all people with disabilities” (Waldschmidt, 2009:9), the impact of Italy incorporating social policy for disability rights within pre-existing social welfare policy is also relevant to consider in addressing issues of equality. It is therefore of significance to address the issue of recruitment in my study, which uses the medical framework in the form of categorising women within the Expanded Disability Status Scale (EDSS) to select my participants.

2.11.2 Application of the Social Model of Disability.

To aid recruitment, it was necessary to lay out specific criteria for my study sample, as will be discussed further within the methods chapter. In order to facilitate this and to ensure that I was able to address potential differences in my participants’ experience, according to their level of impairment, it was necessary to use a commonly recognised tool to demarcate those levels of impairment. I therefore used the Expanded Disability Status Scale (EDSS), which is one of two widely used and recognised means of measuring disability in people with MS (National MS Society, 2013). However, my study sought to highlight the socially constructed barriers that impact on the lives of disabled people, rather than concur with a medicalised construction of disability. Despite the use of the EDSS to assist with recruitment, the aim of my study was to demonstrate the social and

environmental barriers that disabled women face during motherhood. My study will therefore report the findings in accordance with a social model of disability, highlighting barriers to equality for disabled mothers, rather than relating disability to their impairment. That said, there are arguments to suggest that issues of impairment are indeed relevant to include within the framework of the social model of disability, and that attention to individual experiences of specific impairments, does not undermine the political force of the social model of disability, but instead enhances the accounts of disability (Barnes & Mercer, 1996). One of the criticisms of the construction of the social model of disability is the failure to identify the distinction between the impairments that people have, and the oppression which they experience (Shakespeare & Watson, 2001). Furthermore a number of disabled feminists have recognised that the social model of disability neglects the relevance of individual experience of impairment (Watson, 2012). My study will highlight issues related to levels of impairment to describe the personal experiences of disability, but frame these within a discourse that attributes the source of disability within socially constructed barriers, rather than within the specific impairments themselves. This is particularly pertinent to recognise as within the current Italian discourse on disability, there continues to be a focus on the source of disability as being with the individual rather than within societal barriers.

For example, data on the number of disabled people in Italy defines people as being disabled as “people that during the interview declared themselves unable to perform independently an essential task of everyday life” (ANED, 2011) and in a recent statement discussing a disability bill, the Italian Minister for Disability Equality stated “We cannot allow that the disabled should be made to feel more different than they are” (www.equalityitalia.it). Although it is possible that issues of translation have influenced

the grammar and the words used in these two examples, the underlying implication that disabled people are viewed as being “different from the norm” suggests that there is still some work to be done in addressing attitudes towards disability in Italy. This lack of appreciation of the potential reinforcement of oppression of disabled people, through the use of individual approaches to disability is relevant to my study. Comparing how disability is constructed within the medical and social models of disability is important as:

“The language that people use reflects what they think and can influence how they deal with situations. If they behave as if the problem is with the individual, they will take a different approach than if they regard the problem as being with the attitudes, systems and practices that create disabling barriers.” (Clark & Marsh, 2002:1).

Despite the use of the EDSS to assist with recruitment, the use of language as a medium for reinforcing barriers to disabled people is fundamental to my research, and disability will be represented in terms of the social model, rather than within a medicalised framework, to avoid potential reinforcement of negative stereotypes associated with disabling language. Examining the experience of disabled people in a society which continues to use terminology which implies an individualised approach to disability raises issues about how disability is represented not only in language, but also in the culture of Italy, and the Catholic Church has a potential strong role to play within Italian culture (Garelli, 2007).

2.12 The Influence of the Catholic Church.

The Catholic Church has a significant role to play in moderating the political agenda in Italy (Naldini & Saraceno, 2008) and with its social agenda of reducing inequality (Garelli, 2007) it could therefore be speculated that the church has a potential positive role to play in addressing issues of inequality for women. Conversely, in considering the impact of the patriarchal model of the Catholic Church, it is proposed by some feminist researchers that women are seen as being inferior to men and should therefore aspire to be passive and obedient (O'Connor & Drury, 1999). Therefore the indoctrination of the Catholic Church, as well as influencing the political agenda, also impacts on the culture of Italy (Naldini & Saraceno, 2008; Garelli, 2007) and may influence how my female participants view their roles within society. In fact, in Italy it is difficult not to be aware of the diffuse and pervasive presence of the Catholic Church and its extensive influence on Italian society (Garelli, 2007). Garelli (2007) suggests that Catholicism in Italy, with which the majority of the population identify, manifests itself as an affiliation to culture and tradition, rather than with religious beliefs. Investigating issues of inequality and oppression within a society which is so strongly influenced by the Catholic Church therefore adds a further dimension to studying the experiences of disabled women. I will also now consider the literature around the position of women in Italian society.

2.13 Women in Italian Society.

Within Italian society there is a lack of equality of opportunity for women (Michaels, 2009; The Guardian, 2011), although Italy once had a thriving feminist movement. In the late 1960s and for most of the 1970s, there were huge steps forward for women in Italian society. The right to divorce in 1970 (confirmed in a 1974 referendum), as well as reforms

in family law, the legalisation of family planning (both in 1975), and the legalisation of abortion in 1978, all led to greater legal, financial, and personal security for women. Despite the strength of this feminist movement, the political agenda in Italy has remained “gender blind” (Sundström, 1999:198) and the influence of feminism as a whole was relatively inconsequential. In fact “Italian feminists remained unheard in the international arena of modern feminist discourse until translations of their writings into English began in the late 1980s” (Aderlini-D’Onofrio, 1994:213). In spite of a recent resurgence of the feminist movement in Italy (Michaels, 2009), social policy continues to favour a patriarchal family model, reducing choices for women and continuing to maintain the traditional family set up, with women taking responsibility for care (Miller, 2001).

Italian social policy is not conducive to enabling women to maintain the role of both mother and paid worker, because of the combination of a lack of provision of early years education and child care and inflexible working opportunities (Miller, 2004). The lack of part time or flexible working conditions also impacts on employment and the assumed role of mothers, that is that they will stay at home and provide full time child care, along with informal care for other relatives. Although there has been a recent increase, a high percentage of women in Italy do not work, despite more women graduating than men (The Guardian, 2011). Research shows in relation to women who have children, this is largely because there are few opportunities for part time work (Sundström, 1999), but also because there is a lack of high quality affordable child care (Miller, 2001). It is suggested that for Italian women, the choice is either motherhood or work, the two cannot be combined together (Mabilia, 2010), which is underscored by the cultural expectations of the role of women in Italian society. There is therefore a potential conflict for women between their socially constructed aspirations for financial autonomy and

their desire to become and to be completely absorbed in their role as a mother (Mabilia, 2010). These two roles, of mother and of successful financially independent women, are seen as two separate entities “roles have turned into prisons; they are seen as mutually exclusive instead of harmoniously coexisting aspects of a person’s life” (Mabilia, 2010:39).

European statistics report that the percentage of women who are ‘inactive’, due to family responsibilities, is almost 31% in Italy. This figure is surpassed only by Greece and Luxembourg, who have slightly higher percentages of women who are not economically active due to family responsibilities, with the UK having just 14.1% of women in this position (Eurostat, 2003). Therefore for all women in Italian society there are indications of social oppression; with inadequate access to facilities and opportunities to enable women to combine the demands of work and childcare. These stereotypical images of women and the limited legislative support to redress issues of inequality, will also impact on women who are disabled and are explored in my study. How my participants view their roles as mothers is influenced by the images of women represented in everyday society, which become embodied into cultural expectations. Whether women are drawn into this uphill battle against Italian culture and how they perceive themselves and their life roles gives an interesting insight. Other westernised countries are campaigning for issues around improved paternity leave and enhanced childcare provision for working mothers, whereas in Italy, the agenda is around women demonstrating that they have a mind as well as a body (The Guardian, 2011). How women who are disabled experience their roles as mothers is therefore particularly relevant to explore in Italy, where the huge gender gap in equality in employment and financial independence, undoubtedly impacts on the role of women; and how the cultural differences and expectations of women in

Italy compares to the literature on the experiences of disabled women from the UK and USA where the majority of the literature materialises.

Within the feminist and disability literature, it has been suggested that disabled women are “doubly oppressed” on account of them being both women and disabled (Reid et al., 2003). Although there have been arguments to suggest that this portrayal is unhelpful, as it further reinforces the stereotypical images of disabled women (Morris, 1992); for women in Italy, this double oppression is in fact seen to be a reality. As indicated above, inadequate social policy to address the rights of women has led to an imbalance of equality in the social world compared to men, and further potential oppression due to disability is also significant.

2.14 Summary.

In searching the literature on disability and parenting, I found a distinct focus on parenting of disabled children, rather than reference to disabled people as parents.

However, there is a small, but growing body of literature on the experience of disabled parents, primarily due to efforts from within the disability movement (Thomas, 1997).

Whilst the above evidence comes from a range of different cultural and national contexts, making it difficult to draw direct comparisons, there appear to be some commonalities. These are that the attitudes of professionals and society as a whole affect the autonomy and empowerment of disabled parents and also how practical support and social policy are implemented. It is also evident that disabled people often do not seek the support they are entitled to, due to a fear of their competence as a parent coming under scrutiny (Wates & Jade, 1999; Olsen & Clarke, 2003; Prilleltensky, 2004; Goodinge,

2000; Grue & Laerum, 2002). However, there is also evidence that formal support is not taken up due to disabled parents being unaware of what is available, and professionals either lacking awareness of appropriate existing services, or failing to adequately promote them. It is also suggested that professionals form subjective opinions on the parenting abilities of disabled people, which in the UK, combined with media interest and an increase in social policy on “young carers”, reinforces a medical model of disability, portraying disabled people and their children as being a welfare concern, rather than addressing the underlying issue of appropriate support. The accounts of disabled people frequently describe the barriers they have to face, in exerting their right to parent children. It is proposed that:

“Whereas the essential support needs of disabled parents are no different from those of any parent...the additional barriers faced by disabled parents can make these needs more difficult to meet...” (Olsen & Clarke, 2003:63).

However, despite the conflict with the empirical evidence (Farber, 2000), there continues to be a negative association between parental disability and effective parenting. Although there is a vast array of research and media literature on the topic of parenting, there is a paucity of literature in the field of social research that addresses parenting as a distinct issue for disabled people, despite the growing number of disabled people who are choosing to become parents. This dearth of studies, combined with an absence of reference to disabled parents within anti-discriminatory legislation, has led to the suggestion that “the mainstream discourse of disability does not blend easily with the mainstream discourse of motherhood” (Grue & Laerum, 2002:672). My study

investigates these two issues concurrently, examining the experience of motherhood, alongside the experience of disability and the relationship between the two.

The overall aim of my study was to explore the lived experience of disabled mothers in Italy and the research questions were guided by the above literature review. My research questions were:

1. What factors have impacted on the women's roles as mothers since the onset of their MS?
2. Is the time of diagnosis relevant to the impact of MS on the women's experience of motherhood?
3. In what ways do wider influences in Italian society, such as the church and the legacy of a government led by Silvio Berlusconi, impact on the lived experiences of disabled women in Italian society?
4. How do external barriers, such as environmental, societal or attitudinal, impact on the women's experience of being disabled mothers?
5. In what ways does this empirical study on the experiences of Italian women with MS contribute to the wider understanding of issues around disability and motherhood?

In view of the existing literature outlining the role of professionals in governing formal support and allocating resources, one of my questions was to explore how my participants have maintained their role, by investigating any formal care they received and their views on this. As the literature also highlights the role of informal support, my research questions also addressed how my participants viewed any informal support they received from family and friends. Linked to this, another of my research questions was to

look at any socially constructed barriers my participants faced, not only from professional attitudes, but also from society in general, including environmental barriers. In light of the socio-political context of disability, as discussed above, a further aim of my research was to explore how social policy in Italy impacts on the lives of disabled people, particularly for my participants as women. My findings will add to the limited discourse on disability and motherhood, from the perspective of women living in Italy, but also have wider relevance for professionals working with disabled mothers, who to date have had access to a limited body of literature which has been mainly grounded in the medical field.

As can be seen from the literature reviewed, there is a complex intertwining of policy and social influences on how issues effecting disability are defined. These multifaceted frameworks from the medical and social research fields have influenced this literature review and have informed the methodology and methods of my research. The following chapter will explore these issues further.

Chapter 3 – Methodology:

3.1 Introduction.

In outlining the research paradigm applied to my study, my fundamental epistemological approach to my research was particularly important to consider, as influential factors included my role as a health care professional, and my personal and professional experience of disability. As such, my methodological approach viewed disability as a form of social oppression, rooted in the inequalities people with impairments face, as a result of barriers society has constructed and continues to reinforce. Furthermore, as a woman and mother, issues around the social construction of gender and parenting will also be significant in my approach to my research.

As my study focused on the lives of disabled women, it concerned itself with issues affecting the experience of being; as both a woman and a disabled person. In undertaking a study that sought to empower my participants, the groups that seek to redress the oppression of women and disabled people were therefore of inherent interest, and guided the methodology for my study. Academic discourse from both the feminist and the disabled people's movement were therefore fundamental to my study and will be explored within this chapter in order to outline how the endeavours of both these groups seek to redress the oppression and inequality of those they represent. Firstly though, I will outline the central ontological and epistemological approaches that underpin my study.

3.2 Ontology and Epistemology.

Ontology is the study of being and is underpinned by philosophical foundations (Crotty, 1998; Wilding, 2011). As such one's ontological standpoint is the basis of how one views the world, how one interprets the essence of being. It has been proposed that positivistic and subjectivist ontologies are at two ends of a spectrum; and that ontology represents one's fundamental beliefs about human beings and their world (Morgan & Smircich, 1980). In this way, ontology makes assumptions about the world, with positivistic ontology seeing the world as being separate from human meaning-making (Potter, 2006), by viewing reality as an absolute (Wilding, 2011). In contrast, subjectivist ontology postulates that reality is contextually bound (Wilding, 2011) with human beings being inextricably linked to their world. My ontological approach is more analogous to subjectivist ontology, which associates with my rationale as a researcher of lived experience, as my view is that in order to examine certain phenomena, one must consider this within the context of human interaction in the world.

Closely linked to ontology is epistemology, which is described as "a way of understanding and explaining how we know what we know" (Crotty, 1998:3) and Smith et al propose that "epistemology is a conceptual issue with a practical impact upon the research we do which emerges in data analysis" (2011:46). Therefore one's fundamental epistemological approach is related to how the praxis of research is conducted, which ultimately impacts on how data is analysed. There are a number of different epistemological standpoints (Crotty, 1998), which are often divided into objectivism, constructivism and subjectivism. Within these definitions of epistemology, my position would accord with a constructivist epistemology, that is, meaning is constructed rather than being one single reality waiting

for discovery (Potter, 2006; Crotty, 1998). A constructivist epistemology therefore allies with an underlying subjectivist ontology. In contrast positivistic ontology corresponds with an objectivist viewpoint, or epistemology. However Whaley (2001) applies a different categorisation of epistemology, and distinguishes between positivist and feminist epistemologies. Within the feminist epistemology it is believed that value free research is not feasible and that context is critical in understanding why people behave as they do (Whaley, 2001). This definition of feminist epistemology therefore has associations with constructivism and a postmodernist view that knowledge is created through people's meaning making (Potter, 2006). My epistemological standpoint therefore accords with both feminism and constructivist approaches.

Qualitative research is now more commonly associated than it was with the traditional epistemologies of health professionals (Wilding, 2011) in which knowledge is created through a "relative interaction between knower and known" (Wilding, 2011:3). As such, a qualitative study "explores the textured meanings and subjective interpretations of a fluid, uncertain world" (Finlay, 2011:9) and its main strength is that it highlights the context of the study (Ball et al., 2011), which accords with the definitions of both feminist and constructivist epistemologies described above.

In undertaking a qualitative study, I am aware that there is no fixed way of classifying qualitative research (Patton, 2002 in Smith et al., 2011). Ball et al go further in defining the term qualitative as representing "a logical grouping of related concepts used to draw several different aspects together that are relatively and complexly intertwined" (2011:303). When considering my desire to produce research that was empowering for the participants, I was mindful that "multiple definitions of feminism result in multiple

feminist perspectives on social research methods” (Whaley, 2001:420) and that there are over forty methods in qualitative research (Smith et al., 2011). Consideration will now be given as to how feminist perspectives influenced my research methodology, alongside the influence disability theory had on my study.

3.3 Feminist & Disability Theory and Empowerment.

Both disability and feminist theorists are concerned with the eradication of inequality and oppression of the people they represent (Watson et al., 2004), although they differ in how they address these issues. One of the divergent debates for feminists and disability theorists is that of the concept of care (Watson et al., 2004). The feminist ethics of care “is based on a recognition of interdependence, relationships and responsibilities, and criticises notions of autonomy, independence and individual rights as being too much based on a masculine view of people as separate from each other” (Morris, 2001:25). This causes some potential conflict with the autonomy and right to independence sought by disabled people, as the notion of care significantly contributes to their oppression due to the view that disabled people are in need of being ‘cared for’ (Watson et al., 2004).

Disabled people have therefore sought to redefine care and assistance in terms of the social model of disability, conveying the social barriers that obstruct their participation in society. Although this construction of care disregards the personal experience of disability and impairment (Watson et al., 2004), which some have argued is essential to consider (Morris, 1992). In fact Lloyd (2001) suggests disabled women battle with opposing interpretations of care – the dependency proffered by the disability movement and the oppression from giving care proposed by feminists. For feminists, the oppression caused by care is due to the assumed responsibility women take in caring for others. “Caring

work is often assumed and silently demanded from mothers and women more generally” (Watson et al., 2004:333). It is suggested that care and caring activities are socially constructed concepts (Watson et al., 2004) and it is argued that “...at least in the UK, care is regarded as a byword for dependency and so a means by which disabled people’s lives are colonized and controlled” (Watson et al., 2004:335). Morris (1993a) also describes how society sends conflicting messages to disabled women, concluding that they are incapable of fulfilling the roles of homemaker, wife and mother. The dependency and passivity linked to these roles matches the stereotypical depiction of disabled people as being dependent and passive. However, whilst society links such traits with both disability and motherhood, it does not view these roles as being compatible.

Whilst seeking to integrate feminist and disability theories into my research I am aware that there is no singular feminist method for research (David & Sutton, 2004). Morris defines two significant bearings feminism has had on academia in the 1970s- 1990s. The first she describes as the inclusion of women into the male dominated perception of the world, what she terms “adding women in” to the research discourse (Morris, 1993b:58). But the second, more revolutionary influence she defines was the challenge feminists made to existing research theories and methodologies, to make them compatible with explaining the reality of experiences for women. In doing this, feminists introduced the value of the personal subjective experience of women, but also transformed paradigms, theories and philosophy of considering feminist approaches to research (Morris, 1993b). Whilst first wave feminist fought for formal equality, second wave feminism in the 1960s and 1970s extended and questioned the meaning of equality, suggesting consideration of the differences of women (David & Sutton, 2004), rather than assuming equality meant striving to become equal with men in a predominantly male led society.

Although there have been some differences in how feminists and disability activists have addressed the sources of their oppression (Morris, 1993a) they have similar goals. Both disability and feminist theorists seek to highlight and redress issues of inequality and oppression (Watson et al., 2004), although disabled women have tended to fall between the gaps of both feminist and disability discourse (Radcliffe, 2008). In the past, studies which explored the experiences of life as a disabled person have tended to focus on taking a medical model view of disability, rather than a social model approach. Within the medical model construction of disability, the disabled person is the source of the issue, their impairment is seen as the “problem” that must be resolved. In contrast, with the social model definition of disability, the disabled person is a person who has an impairment, who, due to the structure of society and the barriers it presents, disables a person with an impairment by subjecting them to oppression. This oppression of a disabled person can be likened to other prejudices and oppression of other societal groups; such as how women are oppressed on the basis of their gender, black people are oppressed on the basis of their skin colour and gay people are oppressed on the basis of their sexuality. In order to expose this oppression - what could be referred to as “disablism” of disabled people - their voices need to be heard. It has been stated that “... it is possible to expose disablism through narrative accounts of personal experience” (Watson et al., 2004:339). Therefore a means of exposing the views of disabled women would be through hearing their stories, and Morris (1993a) argues that the central tenet of feminism, “the personal is political” needs to be embraced by researchers undertaking research with disabled people, in order to give a voice to subjective experience. My research therefore adopted a qualitative approach, in using narratives to explore the subjective experience of life as a disabled mother. Through using this approach I aimed to embrace an empowerment perspective, by uncovering the sources of oppression for my

participants, rather than assuming that any barriers to them fulfilling their roles could be addressed simply by approaching my study as an exercise to identify unmet support needs. It also identified how the participants could be more empowered, by clarifying issues around choice and satisfaction with any support and services that they received, and discussing how society responded to them as disabled people.

Similarly to Morris, a significant contributor to academic discourse around feminism and disability, I was “seeking to incorporate a feminist and a disability rights perspective into my research” (Morris, 1992:158). In view of the oppression of both disabled people and women and my consequent desire to embark on a study which was empowering, it is relevant that qualitative research “places the participant as the “experiencer”, in the position of expert and the investigator in the position of learner” (Wilding, 2011:4). As stated above, my research was qualitative in nature and therefore qualitative methodology needs to be considered.

3.4 Qualitative Methodology.

Within health research, there has been a prevailing reliance on positivist scientific approaches to research enquiry (Green & Thorogood, 2005), but there has been recent significant growth in qualitative research in health research, which offers the potential to provide detailed investigation of interwoven topics (Yardley, 2000). I chose to adopt a qualitative methodological paradigm for my study, which relates to my underlying ontological and epistemological perspectives as described earlier, as well as my wish to encompass disability and feminist exemplars in my research. Mackenzie (1994) states that the terminology used in qualitative research is frequently confused and that there is a

lack of clear literature that defines methods, which is perhaps unsurprising considering the array of methods available to a qualitative researcher. It has been suggested for example “There is no consensus on the boundaries between terms such as narrative, biography, life history or life story and researchers use the terms in overlapping and different ways” (Temple, 2006:8). Smith et al (2011) do attempt to provide a classification for qualitative research and suggest a means of dividing the purpose of the research into three groups. They split these into “understanding the use and meaning of language” which is compatible with discourse analysis and conversational analysis; “developing theory” which corresponds to adopting a grounded theory method; and “describing and interpreting participants’ views” for which they suggest qualitative content analysis, thematic analysis and phenomenology.

In order to clarify my methodological standpoint I considered phenomenology and its applicability to the aims of my study. Finlay defines the aim of phenomenology as being “to describe the lived world of everyday experience” (2011:10). In considering issues of mothering as a disabled person, I aimed to give the reader an informed insight into the lived world of being a disabled mother in Italy. Adopting a phenomenological approach therefore accorded with the fundamental aim of my study. I was also mindful that researching the everyday world of mothers within this setting, epitomises a “highly complex, situated phenomena of occupation” (Wilding, 2011:19), due to the lack of exploration on this occupational role previously conducted within this geographical and cultural context, in the framework of disability. Thereby phenomenology was arguably an important research methodology to be employed. I used a phenomenological methodology in my research “...in order to access and describe lifeworld experience, as opposed to explaining how or why the meanings arise” (Finlay, 2003:160).

Phenomenology has seen a rapid growth in qualitative research, not least by health care professionals and occupational therapists (Wilding & Whiteford, 2005; Clarke, 2009), due to the links between its underlying philosophy of human centeredness and the humanistic approaches on which many health professionals' values and beliefs are based (Finlay, 1999). Despite this increasing uptake, there is much confusion within the literature as to what constitutes a phenomenological approach (Finlay, 1999; Norlyk & Harder, 2010), not least because those claiming to conduct phenomenological research rarely give adequate details of the methods they employed (Finlay, 1999). However Finlay (1999) suggests that despite phenomenological theorists having different foci, there are some common principles applicable to all variants of phenomenology to a greater or lesser degree. I will therefore set out my understanding of phenomenological theory and praxis.

3.5 Introduction to Phenomenology.

As it facilitates a depth of exploration, phenomenology is suggested for use in areas where there is little published material (Wilding, 2011), which is the case with the scarcity of literature on the experiences of disabled parents. Essentially, phenomenology provides "insight into the meaning of lived experience" (Starks & Trinidad, 2007:1376) and is used to study the "everyday aspects of humans" (Wilding, 2011).

However, as indicated above, there has been difficulty in firmly defining a phenomenological approach to research. A systematic review of peer reviewed nursing journals of published phenomenological studies, concluded it was "unclear what makes a phenomenological study phenomenological" (Norlyk & Harder, 2010:429). Having

considered thirty seven articles, which were identified as phenomenological by the authors, Norlyk and Harder (2010) found considerable variation in how the studies were defined, ranging from brief to detailed descriptions of the chosen phenomenological approach, and inconsistencies in methodological clarity and rigour. Indeed phenomenological research is said to be “one of the most philosophically and theoretically complex research traditions” (Wilding, 2011:2). When considering undertaking a phenomenological approach, I was mindful that there are specific theoretical and philosophical influences which underpin this type of study (Wilding, 2011), although as discussed, these are not always fully adhered to or applied within studies claiming to be phenomenological. The following section will therefore outline how these influences apply to a phenomenological approach.

3.5.1 Philosophical Foundations of Phenomenology.

Philosopher Edmund Husserl is credited with the original establishment of phenomenology (Wilding, 2011; Pringle et al., 2011a). Husserl’s approach was extended by later philosophers, such as Heidegger and Gadamer, who developed a more interpretative approach (Pringle et al., 2011a). Heidegger is recognised as founding hermeneutic phenomenology (Crotty, 1998) which moves the study of phenomena beyond description to interpretation, and his phenomenological construction is perhaps more in keeping with the philosophy of occupational therapy concerning the value of everyday life (Wilding, 2011).

Although some have questioned whether purist phenomenology is interpretative (Jones, 2001), the aim of hermeneutic phenomenology is to interpret the meaning of what has

been revealed or described, and the word 'hermeneutics' is derived from the Greek word meaning "to interpret" or "to understand" (Crotty, 1998). Therefore any study that claims to interpret its results must to some extent be adopting a hermeneutic approach to analysis (Pringle et al., 2011a). Hermeneutic phenomenology provides a means of "accessing, interpreting and communicating human experience" (Standing, 2009:29). Heidegger centred on how interpretation is inherent to human existence (Todres & Wheeler, 2001) and argued that the meaning in people's lives is given by the context of the world in which they live (Wilding & Whiteford, 2005:7). This Heideggerian concept of "Being-In-The-World" (Todres & Wheeler, 2001) signifies that human beings and the world cannot be considered as separate entities as they are interdependent. Therefore the lived experience of human beings can only be considered in relation to their life context.

Two of the essential features of hermeneutic phenomenology are the "hermeneutic circle" and "fusing of horizons" (Wilding, 2011). The hermeneutic circle describes the dialectic interchange between the parts and the whole to facilitate a gradual understanding of the phenomena. This involves reflexivity on the part of the researcher and necessitates prolonged and repeated attention to the words and stories of the participants (Wilding, 2011). This is necessary as hermeneutic phenomenology involves not only interpretation of the data, but also "self-interpretation" (Todres & Wheeler, 2001:2), in recognising and acknowledging the inherent role of the researcher in undertaking the interpretation.

The concept of 'fusing of horizons' originated from the work of Gadamer and refers to the combination of influences that make a person who they are, including "the social,

historical and political contexts in which they live” (Wilding, 2011). This is applicable both to the participants, but also to the researcher, who will need to assent that their interpretation is “always mediated and influenced by one’s own experiences” (Wilding, 2011:12). It is essential to identify, examine and challenge one’s own preconceptions as these can be overlooked and are an essential element of hermeneutic derived research (Todres & Wheeler, 2001). As a woman, mother and professional who has both clinical and personal experience of disability, I needed to be mindful of the impact these influences and experiences could have on my interpretation of my participants’ stories and recognise Husserl’s assertion that biases and predispositions will “never actually (be) transcended” (Wilding, 2011:12). The concept of disregarding one’s pre-existing beliefs and ideas is what other phenomenological philosophers, including Husserl, have referred to as “bracketing” and will be discussed later.

In acknowledging the influence of my experiences and biases, it is of relevance to reflect that my interpretation of my participants’ words is just that, an explanation of my understanding of the experience, rather than an exact or correct account. I sought to give what Van Manen referred to as “plausible insights” (Wilding, 2011) into the experiences of my participants.

Put simply, “phenomenology is the attempt to describe individuals’ experience and it “seeks to move beyond appearance to grasp underlying, essential meaning” (Finlay, 1999:301). The fundamental aim of my research was to explore the meaning of being a disabled mother in the Italian context. Implicitly then, uncovering the meaning behind the issues raised will be a necessary part of my analysis. Phenomenology has been described as a “family of research methods” (Cassidy et al., 2011:264) and phenomenological

analysis involves production of “rich thematic descriptions that provide insight into the meaning of the lived experience” (Starks & Trinidad, 2007:1376). Writing anecdotes or stories, which are drawn from different accounts of my participants to formulate an amalgamated description of the experience of being a disabled mother in Italy is one of the intentions of my study (Starks & Trinidad, 2007). However, my study went beyond a description to provide an interpretative account of life as a disabled mother in Italy. As Finlay states, the challenge with phenomenology is to go beyond the verbatim data to “intuit implicit meanings” (2011:16). I therefore needed to select an approach which corresponded with phenomenology which would facilitate me in gaining meaning from the data, that is, to select a method of analysis and to put phenomenology into practice. Prior to this, I will firstly explain the choice of data collection tool used for my study to show its compatibility with a phenomenological approach.

3.6 Data Collection.

Second wave feminism judged quantitative methods as being more objectifying in their approach, whereas methods such as in-depth interviewing offer a more egalitarian approach (David & Sutton, 2004). It is suggested that the use of narratives in relation to research around illness “stem from a secular desire to limit the sometimes dehumanising effects of a medicalised society, and the effects of forms of medical practice that deliver increasingly technical sophistication but fail to offer ‘comfort and care’ for patients as whole human beings” (Bury, 2001:282). Applying a phenomenological approach requires understanding by “asking how the person’s *world* is lived and experienced” (Finlay, 2011:3). Interviewing is a frequently relied on method of collecting data in qualitative studies, with a semi-structured format being suitable for phenomenological studies

(Starks & Trinidad, 2007; Shaw, 2001; Smith & Osborn, 2003) and this method of data collection was used in my study. Through using interviews to hear my participants' stories, I was enabling a holistic view of their lives, facilitating an alternative view of chronic illness by exposing my participants' day to day lives and the barriers they faced, rather than adopting a medicalised focus. In this way, by emphasising my participants' lived experiences as mothers, rather than solely focusing on their MS, my research facilitated an empowerment perspective by shifting the responsibility for disability to external barriers, rather than the women's impairment. Although Oliver (2002) suggests it is naïve to assume that identifying with research participants gives sufficient grounds on which to suggest relevant accounts of experience are being reported, by listening to the stories of my participants I was "positioning them centrally as agents and collaborators in [my] intellectual work." (Ferber, 1999:271). In this way, using interviews to hear the experiences of my participants promoted the fundamental aim of my research to enable disabled women's voices to be heard, and using interviews to gather data is conducive to realising feminist research goals (David & Sutton, 2004).

Semi-structured interviews offer a flexible approach to understanding experience which also maintains a contextual focus (Clarke, 2009). Over structuring an interview can lead to an inadequate recognition of the differences between languages and limit the scope for delving deeper for responses, for fear of then misrepresenting the questions (Larkin et al., 2007), so questions should be exploratory and semi-structured (Cassidy et al., 2011:266). In light of this and the issues with language difference, which will be discussed later, the format of semi-structured interviews was used for my study. The following section will explore how my adoption of a narrative approach relates to the praxis of a phenomenological paradigm.

3.7 The Praxis of Phenomenology.

Within phenomenological studies, the role of the researcher is one of inquisitiveness and the researcher acknowledges their subjectivity in the research (Finlay, 2011). The relative interaction of the researcher in the data positions the researcher as one who must interpret, understand and describe (Wilding, 2011). As a researcher who continued to be involved in clinical practice and who aimed to create research which had relevance to the clinical field, I endeavoured to find a research approach that was compatible with my epistemological beliefs and my professional practice. As already outlined, my chosen approach was phenomenology and my research aimed to produce qualitative data through conducting in-depth interviews, and this approach was compatible with my epistemological standpoint.

However, Crotty (1998) has argued that the distinction between qualitative and quantitative research does not emerge from one's epistemological perspective, but at the level of methods. Starks and Trinidad (2007) take this one step further and suggest that a distinction should be made between the goals of each method; discourse analysis, which aims to explore personal, social and political experiences through examination of language, grounded theory which aims to develop theory, and phenomenology which aims to explore how people make meaning of their lived experience (Starks & Trinidad, 2007). The goal of phenomenological methods thereby accorded with my central research question, which was to produce an account which embodied the lives of disabled mothers, and is compatible with using interviews to hear the stories of lived experience. Starks and Trinidad (2007) suggest that phenomenology relies on the researcher writing

and rewriting to gather meaning, in order to produce an account that portrays the important elements of the lived experience. The following section will define how phenomenology was applied to ensuring the words of my participants were actively heard, thus resulting in production of plausible insights.

3.8 Analysis of Phenomenological Studies.

Following data collection, it was necessary for me to conduct an interpretation of the data, to avoid “merely a static description” (Mackenzie, 1994:780) of the participants’ experiences. On an applied level, due to the origins of phenomenology being philosophical, there are few methodological indicators for applying a phenomenological approach to analysis (Wilding & Whiteford, 2005). However, Interpretative Phenomenological Analysis (IPA) offers a more structured and guided approach and therefore was perhaps more suited to my situation, as a novice phenomenological researcher. Although offering more guidelines than some other phenomenological approaches, at the same time IPA it is not prescriptive and on a practical level, creativity and flexibility are encouraged (Finlay, 2011). Specifically, IPA explores how people make sense of their major life experiences (Biggerstaff & Thompson, 2008; Smith et al., 2009). Smith et al (2009) describe the suitability of IPA when researching “what happens when the everyday flow of lived experience takes on a particular significance for people” which they go on to say commonly happens when something important occurs in one’s life (pp.1). In addition to the major life experience of becoming a mother, the added significance of either becoming a mother with a known diagnosis of MS, or a subsequent diagnosis post child birth, constituted further life experiences to explore. In asking my participants to recall their experiences of motherhood with living with MS, I asked them

to reflect on their lives, and I used IPA to engage with these reflections (Smith et al., 2009).

IPA is fundamentally person centred around the participants (Shaw, 2001) which offers a collaborative approach to research (Cronin-Davis et al., 2009) and views the experts as being the research participants themselves (Reid et al., 2005). IPA therefore offers a method which is conducive both to the empowerment aim of feminist and disability research and the philosophy and ethical code for me as an occupational therapist. Whilst having its roots in psychology, IPA is also increasing in popularity within a wider field of qualitative research (Reid et al., 2005) such as health and social sciences (Smith et al., 2009; Finlay, 2011) and is also being increasingly utilised in the occupational therapy literature (Wilding & Whiteford, 2005). This is in part because it fits with the values of occupational therapy in considering a holistic view of a person (Clarke, 2009) and mirrors the philosophy underlying occupational therapy of being person centred (Wilding & Whiteford, 2005; Cronin-Davis et al., 2009).

As IPA is an evolving approach, it continues to be subject to collegiate development and academic debate (Larkin et al., 2006; Clarke, 2009). Furthermore, due to its comparative novelty, there is a lack of literature that compares IPA with other research methodologies (Cronin-Davis et al., 2009). It has been suggested that IPA differs in its approach from grounded theory, in being data driven rather than theory driven, that is, IPA is inductive and exploratory in its approach (Shaw, 2001). Within IPA studies, it is recognised that in producing the findings of a study, the researcher aims to produce a full and refined understanding of the phenomena, but at the same time understands that a “perfect

understanding of the essence of the experience will always remain hidden” (Cassidy et al., 2011:266). Within a guiding framework of phenomenology, I had to be “fully engaged, involved, interested in and open to what may appear” (Finlay, 2011:23). I also needed to have a clear understanding of the tenets of IPA, particularly in view of its relatively new and rapid advancement as an analytical approach in phenomenology. The following section will explore this further.

3.8.1 Theoretical Underpinnings of IPA.

Jonathan Smith is recognised as the pioneer of IPA (Biggerstaff & Thompson, 2008; Smith, 2010; Fade, 2004). Although it has been suggested that IPA stands “As a methodology in its own right rather than simply a means of analysing data” (Cassidy et al., 2011:264), IPA is more commonly recognised as a method of analysis that draws on phenomenology as the underlying methodology. Like many other qualitative methodologies (Smith, 2004), IPA is idiographic in its focus, studying individuals as they deal with specific situations or events in their lives (Larkin et al., 2006). Smith defines the idiographic focus of IPA as being one of three tenets of IPA, along with the interrogative and inductive components (2004). IPA’s idiographic focus necessitates thorough detailed analysis of each participant’s story prior to commencing cross-case analysis to search for convergent and divergent themes (Smith, 2004). IPA is interrogative in that it discusses its findings in relation to pre-existing literature. The inductive approach of IPA allows themes to emerge from personal accounts of participants, rather than trying to impose a predetermined theory (Clarke, 2009) and requires researchers to allow “unanticipated topics or themes to emerge during analysis” (Smith, 2004:43). It enables the understanding of an

experience, rather than being theory forming and seeks to identify what is said, but also what is meant (Cronin-Davis et al., 2009).

The creative approach facilitated by IPA (Wilding, 2011) is particularly useful when researching “unusual” groups (Pringle et al., 2011b). Although not asserting that my participant group fall within this category, the fact that their experiences have not previously been reported in the literature renders interpretation of their experience atypical and therefore perhaps “unusual”. Reid et al posit that “IPA is particularly suited to researching in ‘unexplored territory’ where a theoretical pretext may be lacking” (2005:23). Therefore in view of the lack of empirical studies on disability and motherhood, particularly in the context of Italy, it would seem apt to use IPA when conducting such a study. IPA is promoted for its capacity to investigate human experience within a cultural context; placing emphasis on contextual factors, which may influence the meaning of experience for participants (Shaw, 2001). Indeed sensitivity to context is one of the four broad principles to be considered in validating qualitative research (Yardley, 2000). This focus of IPA on contextualised accounts of experience enhances its suitability when considering cultural issues (Reid et al., 2005) which is relevant to my research being conducted in a different cultural environment.

As is indicative within the name, the primary philosophical base to IPA is phenomenology (Cronin-Davis et al., 2009; Clarke, 2009), but IPA also draws on hermeneutic principles (Smith, 2010). Finlay (2011) suggests that what distinguishes IPA from other hermeneutic approaches is its focus on the individual and how it gives precedence to the consideration of participants’ sense-making. IPA is therefore phenomenological in that it pursues an insider perspective on the lived experience of individuals; but interpretative in that it

recognises the researcher's a priori knowledge and sees interpretation as a prerequisite to understanding (Fade, 2004). By acknowledging the interpretative element of IPA, it is therefore more analogous to the hermeneutic phenomenology philosophies of Heidegger and Gadamer.

Another theoretical influence on IPA is symbolic interactionism (Smith, 1996 in Cronin-Davis et al., 2009), which supposes that people assign meanings to events (Cronin-Davis et al., 2009), and suggests that it is only possible to understand the meaning a person gives to an event through a process of interpretation (Biggerstaff & Thompson, 2008). IPA also draws on the work of Schleiermacher, who states that interpretation does not follow a set of prescribed criteria, but is more of an art form which involves amalgamating skills, including the use of intuition (Smith, 2007). Smith challenges the use of the term "art" and counters that the qualities used within hermeneutic phenomenology also establish its exemplification as a science. Schleiermacher's influence introduces the concept of "intersubjectivity" (Smith, 2007:5) that the words of the participant and the researcher's interpretation of them are crucial. Thereby IPA researchers, in common with other hermeneutic researchers, use interpretation and "accept the impossibility of gaining direct access to participants' experiences" (Finlay, 2011:140). The influence of the researcher is transparent, thereby enabling "a holistic analysis of the interpretative process" (Smith, 2007:5). My role as a researcher was to utilise IPA to interpret my participants' accounts in order to understand their experience (Smith et al., 2009), rather than asserting to be existent in the experience with them.

Whilst being mindful not to focus too deeply on the methodological underpinnings of my study as "engaging too intensely in methodological awareness can hinder the practice and

progress of a research project" (Pringle et al., 2011a:7), I am also aware that analysing data is the most complex element of qualitative research (Thorne, 2000). The following discussion will therefore detail how IPA was applied to the conduct of my study.

3.8.2 The Praxis of IPA.

IPA is hailed as a type of analysis which has the potential to answer in-depth questions regarding individuals' experiences (Shaw, 2001). Writing from the perspective of health psychology, Shaw (2001) promotes the use of IPA as a tool for gaining accounts from people with MS, to facilitate an understanding of the significance that the condition has on their everyday lived experience. Similarly to hermeneutic phenomenology's descriptive and interpretive elements, IPA has a two stage process or "double hermeneutic" approach to data analysis (Pringle et al., 2011a; Smith & Osborn, 2003, 2008), with the researcher trying to make sense of the participants trying to make sense of their worlds (Clarke, 2009; Cronin-Davis et al., 2009). The experience of the researcher is therefore influential in meaning making, both in empathising with participants and in trying to understand their experiences. This interpretative element is fundamental in assuring the quality of IPA studies, rather than purporting to be undertaking IPA and producing a merely descriptive account (Hefferon & Gil-Rodriguez, 2011). Reviewing a number of IPA studies, Larkin et al (2006) suggest that some studies which purport to use IPA have lacked interpretative depth and focused on the description of experiences. They recognise "As with so many qualitative methods, IPA can be easy to do badly, and difficult to do well: it demands that a number of rather testing 'balancing acts' are maintained by the researcher " (Larkin et al., 2006:103), not least by ensuring that the flexibility offered by IPA is not interpreted into viewing the approach as a simple one.

Giorgi, who proposes a more scientific approach to phenomenological research, has been overtly critical of IPA (2010, 2011), in part because he considers IPA lacks theoretical grounding in phenomenology. However, Giorgi's source for criticism is focused on a more positivist approach to research. As Smith reproached, the "processes in qualitative research are not the equivalent of the carefully prescribed procedures in quantitative research" (2010:188). Smith concludes that Giorgi's criticisms are based on framing IPA within a paradigm which is not necessarily conducive to human science research (Smith, 2010). Others agree "The richness, individuality and subjective nature of the participants' perspective may at times not be cogent and amenable to the usual scientific criteria" (Jootun et al., 2009:45).

In line with IPA, my research focus was on the perceptions and views of my participants (Smith et al., 2009) and IPA facilitates this by using a two stage approach to analysis. This involves first undertaking a thematic analysis and then progressing to a second higher level, to provide a detailed interpretation of the themes, based on the actual narratives of the participants (Cronin-Davis et al., 2009). This interpretative element enables researchers to "think about 'what it means' for the participants to have made these claims, and to have expressed these feelings..." (Larkin et al., 2006:104). Indeed it is necessary within phenomenological research to continually return to the participant's stories to consider what these narratives mean about both specific aspects and the whole phenomenon (Wilding & Whiteford, 2005). This process of considering the parts of the text in relation to the whole, and the whole in relation to the parts, constitutes the hermeneutic circle (Smith, 2007). This circle delineates that the analysis is not linear and potentially one could become entrenched in continually moving back and forth between

the whole and the parts to get to a deeper interpretation. Although there are a number of stages to the interpretative process in IPA, Smith advocates adopting a pragmatic approach and states “the final interpretation may never be reached...[and] the skill is in deciding when to come out of the circle and commit oneself to speaking or writing, to deciding that one has an interpretation that is good enough” (2007:5).

IPA has its critics, perhaps because its accessible and flexible approach is misconstrued as synonymous with a lack of rigour (Larkin et al., 2006). IPA “does not seek to find one answer or truth, but rather a coherent and legitimate account that is attentive to the words of the participant” (Pringle et al., 2011b:23) and provides a means of increasing knowledge about a particular phenomenon (Clarke, 2009). Using IPA was thereby conducive to investigating the experiences of the phenomenon of being a mother with multiple sclerosis in Italy, whilst enabling a participatory and empowered approach for my participants. IPA is a relatively new approach to phenomenological research and in offering a more structured approach (Finlay, 2011) perhaps addresses some past criticisms of historical phenomenological approaches, which have been said to lack clarity and be overly complex (Pringle et al., 2011a). By reason of IPA being a “young” approach to qualitative research (Larkin et al., 2006), it is still being reviewed as a research tool and due to the variations in how IPA has been applied, it is sometimes difficult to evaluate the existing literature (Clarke, 2009) and there is little literature comparing IPA with other research methodologies (Cronin-Davis et al., 2009). However, the uptake of newer approaches to phenomenological research, such as IPA (other newer approaches are ‘lifeworld’ and ‘first person’ see Finlay, 2011), is increasing (Pringle et al., 2011a, Finlay, 2011) and this adoption of a more “step by step” approach may explain the rapid expansion of IPA (Pringle et al., 2011b; Reid et al., 2005; Smith et al., 2009).

The primary function of IPA is therefore to gain an insider perspective of the phenomena being studied, whilst recognising the key role of the researcher as a core instrument of analysis (Fade, 2004). In view of the fact that IPA, in contrast to other phenomenological approaches, acknowledges the role of the researcher in the interpretative process and does not require researchers to bracket out – or separate - their ideas, it is argued that it has been mislabelled as a phenomenological approach (Fade, 2004).

3.8.3 The Role of the Researcher in IPA.

In considering the role of the researcher, it is vital to be open to new experiences developing, and one may not even be aware of preconceptions and these may emerge amidst the interpretation, as “the process of interpretation changes the fore-understandings to new ones” (Smith, 2007:7).

As mentioned above, one of the ways in which IPA differs from other phenomenological approaches is in regard to recognising and reflecting on the role of the researcher in the analysis of the data (Cronin-Davis et al., 2009). Indeed the role of the researcher as an insider/outsider is a much debated topic in qualitative research (Pringle et al., 2011a). James (2011) suggests though that through using reflexivity, a researcher can hold a dual role of both insider and outsider. James’ background, analogous to my own, involves perspectives as a subjective clinician, what James suggests is an “inside role”, and an “outside role” as an objective researcher. She suggests the combination of these two roles is a very powerful research perspective to hold. She goes on to conclude that acknowledging one’s insider subjectivity as a clinician can be a strength to the research process (James, 2011). It is suggested that in IPA the researcher adopts both emic

(insider) and etic (interpretative/outsider) status (Reid et al., 2005 in Clarke, 2009; Cronin-Davis et al., 2009). Similarly to the experience of other researchers (for example Pringle et al., 2011a) my role as a researcher does not naturally fit either within the insider or outsider categories. My gender is inarguably the most evident category to render my position as an insider. My status as a “*straniera*” or foreigner, who required a native speaker to enable me to conduct my interviews, undoubtedly substantiated my role as an outsider. I have worked with many disabled mothers, including those with MS, and am a mother myself who has had personal experience of disability, but these factors were not overtly recognisable to my participants, precluding me from further insider status.

As a researcher, I had a responsibility to recognise my personal impact on the fieldwork I was undertaking (Larkin et al., 2007). With traditional phenomenological studies, the researcher is required to acknowledge and put to one side their existing knowledge and assumptions, to be open minded to the accounts of the participants, something which is referred to as “bracketing” (Starks & Trinidad, 2007). This covert insider knowledge, such as the factors described above that my participants were not aware of, ordinarily necessitates one needing to “bracket” their pre-conceptions, when implementing a phenomenological approach to a study (Finlay, 1999). However, unlike other phenomenological approaches, IPA incorporates the researcher’s subjectivity (James, 2011) and takes account of the researcher’s experience and its role in comprehending and making sense of reported experiences (Shaw, 2001). Finlay (2002) suggests that reflexivity is a tool to analyse how subjective and intersubjective elements have influenced the research. The applicability of bracketing and reflexivity will now be explored.

3.8.4 Bracketing and Reflexivity.

Suspending one's a priori knowledge and existing assumptions enables the researcher to experience the phenomena through the eyes of the participants, as if experiencing it for the first time. This "bracketing" reflects Husserl's notion of epoché, or phenomenological reduction (Finlay, 1999; Jootun et al., 2009), which enables a researcher to see the world from another's point of view. However, it is recognised by a number of writers that the approach of bracketing one's preconceptions is very difficult to achieve (Finlay, 1999; Wilding & Whiteford, 2005), if indeed a specific requirement for most phenomenological studies. It has been suggested that "all research requires the setting aside of preconceptions to avoid the pitfall of trying to fit findings into expectations" (Pringle et al., 2011a:11). Conversely it is also recognised that this pre-understanding can be beneficial to the research process (Wilding & Whiteford, 2005). Finlay (2008) argues that there is a tension between bracketing these pre-existing understandings and drawing on them as a source of insight. She and others encourage the researcher to engage in reflexive thinking to redress this balance (Finlay, 2008; Jootun et al., 2009). Reflexivity is "thoughtful, conscious self-awareness" (Finlay, 2002:532). In IPA, there is recognition that the researcher uses their experience and theoretical assumptions to contribute to the research process (Cronin-Davis et al., 2009). However, in order to discern that the conclusions from the analysis arise from the actual data collected, rather than from any preconceptions of the researcher, the inclusion of text from the participants is used to reflect how the conclusion have arisen, which is explicitly included in an IPA study (Pringle et al., 2011a). Using specific quotes or metaphors of the participants helps to root the analysis directly in the words of the participants (Pringle et al., 2011b). In acknowledging and exposing the role of the researcher in the analysis, recognition of this through reflexivity is recommended throughout the process of IPA. On a practical level this

involves the researcher keeping a reflexive diary to record details of the nature of emerging interpretations (Biggerstaff & Thompson, 2008). Although some have posited that reflexivity is an optional tool in IPA (Fade, 2004), others have argued that reflexivity is a vital element to all qualitative methods (Jootun et al., 2009). Being reflexive in one's study can also involve referring to colleagues and mentors and keeping a log of thoughts and ideas throughout the analysis (Starks & Trinidad, 2007; Cronin-Davis et al., 2009). Likewise the use of a reflexive diary and field notes also assist with providing an audit trail, which is a necessary element to demonstrating the trustworthiness of a qualitative study (Cronin-Davis et al., 2009). It is important to recognise the difference between reflection and reflexivity, particularly as they are often used interchangeably within the literature (Finlay, 2002). Finlay defines the two concepts as being on a spectrum, with reflection being the "thinking about" at one end, and reflexivity at the opposite end, involving "immediate, continuing, dynamic, and subjective self-awareness" (2002:533). She suggests that this reflexive analysis should commence right from the outset of the research study, with the researcher examining their motivations and assumptions in order to enter the field "with openness and wonder" (Finlay, 2002:536).

In the context of my study, my assumptions and personal and professional experiences of disability have arisen from the culture of the UK and the existing literature on the subject. Thereby having conducted my fieldwork in Italy, in a culture unfamiliar to me and with a lack of available literature on the experience of disability in this context, I was able to enter the field with a greater degree of "openness and wonder" (Finlay, 2008:2) than researching within the familiar field of the UK would have allowed. During the data collection phase, my ability to be reflexive took the form of briefing and debriefing the interviewer pre and post interviews, which will be discussed later. Within my study

overall, part of this reflexive process involved consideration of the inter-subjective dynamics between myself and the data (Biggerstaff & Thompson, 2008) and my analysis thereof, as “Ultimately, the reflexive researcher acknowledges that any finding is the product of the researcher’s interpretation” (Jootun et al., 2009:45). Phenomenological research will always be influenced by subjectivity (Giorgi, 1994 in Finlay, 2002) so rather than trying to eliminate it, acknowledging this subjectivity through reflexivity enables a greater understanding of the researcher’s impact on the study findings.

3.9 Summary on Methodology.

The above discussion has outlined the methodological foundations of my study, including the underpinning research paradigm, and the reasoning behind how my data was analysed. The rationale for using interviews as the method of data gathering has also been discussed, both in terms of their applicability to a qualitative study and as a means of providing an empowerment perspective to the gathering of information. The second section of this chapter will now consider how these aspects were applied to the design and process of my study.

3.10 Methods.

The following sections will explain the techniques and procedures I used to collect and analyse my data, but will also explain the design of my study. In this way, I will now place the methodology into its context, by showing how the theoretical underpinnings of my study were applied to the practice. Firstly, to demonstrate that safeguards were undertaken to protect the study participants, an outline of ethical considerations will be given.

3.10.1 Ethics.

Prior to commencing my fieldwork, I gained approval from the Open University Ethics board and the scientific committee of the AISM (the Italian Multiple Sclerosis society), who assisted me with my study. This ensured I recognised the need to fulfil my legal and moral responsibilities as a researcher (Potter, 2006) and that I complied with my professional code of practice. A copy of my ethical approval is included in appendices 3 and 4, and the following sections will demonstrate how I ensured I met the required ethical conditions. It is also important to note that pseudonyms were used throughout the study write up, to protect the confidentiality of my participants. This includes use of their names, any family names used, and place names were also changed.

3.10.2 Study Design.

As has been indicated, my qualitative study used face-to-face interviews to collect the views of women on the phenomenon as life as a disabled mother. As an English speaker, it is a significant issue that my fieldwork was undertaken in Italy, with Italian speaking

women. On a practical level, the logistics of carrying out my fieldwork were therefore trialled through conducting initial pilot interviews; one in England with an English woman, and one in Italian with an Italian woman. However, there were many more considerations as to potential issues related to conducting a study in another language, not only from a pragmatic viewpoint, but also with regard to methodological considerations. Smith (2004) reflects on the development and the future of IPA and the possibilities of expanding the participant population beyond the usual configuration of individual semi-structured interviews with English speaking adults. He ponders the potential complexities of undertaking an IPA analysis and conducting interviews in a language other than English, and refers to a study conducted by himself and Raval (Raval & Smith, 2003) which has considered the possible issues. This study specifically discusses potential concerns around language in relation to IPA and will be considered in some depth as there is little other qualitative research with reference to working with interpreters and researchers have subsequently had to rely on anecdotal or descriptive evidence (Raval & Smith, 2003). I therefore needed to consider the implications of how my participants' words were translated and represented in English within my analysis.

3.11 The Configuration of My Study.

When exploring the issues around translation, the literature which was found considered the roles of interpreters or translators, rather than considering the specific arrangement my study involved, with a native speaker conducting the interviews and a separate person undertaking the translation. However, to ensure that I considered all the dilemmas and potential challenges to undertaking research in another language, I addressed the issues raised in the literature on translation and interpretation, to demonstrate how safeguards

were adopted in my study to ensure I was faithful to the words of my participants, and to demonstrate rigour in my study.

Berman and Tyyskä (2010) identify that there are a number of different terms to describe the interpreter or translator, such as cultural broker, facilitator, team member; all of which have implied social status and therefore a perceived role. Squires (2008) distinguishes between the roles of interpreters (providing oral translation) and translators, who translate documents, including transcribing interviews; and for the configuration of my study, finding a translator who had both language proficiency and cultural awareness was necessary (Larkin et al., 2007).

Much of the literature on issues of language applies to considerations around when an interpreter is employed to conduct translation of the words at the time they are produced; that is to translate the words of the researcher and the participant at the time they are articulated. However for my study, the interviews were conducted wholly in Italian, with the translation taking place later. Therefore this arrangement allowed more time to apply safeguards in the translation process. To assist me with conducting my interviews, a bilingual speaker was recruited. This woman was a practising occupational therapist who worked for the Italian MS society (AISM) providing rehabilitation services for people with MS within their own homes. For the purposes of the following discussion, this person will be referred to as *the interviewer*. The interviews were audio recorded and transcribed verbatim into Italian and then translated into English. The transcriptions and translations were conducted by an independent person, an English speaking woman who was fluent in Italian. She had lived in the UK for a number of years, having also spent various periods of time living in Italy and she is native Canadian. For the purposes of the

following discussion, this person will be referred to as *the translator*. Within my study, both the interviewer and translator were involved in translating and interpreting in specific ways and could be considered to take the role of '*language intermediaries*' (Edwards, 1998). Their roles will be defined further throughout the following sections.

3.11.1 Working with Interpreters.

Temple (2005) suggests three ways in which researchers have attempted to address issues of cross-language representation. These are: leaving out any reference to issues of cross -language in the work; acknowledging the potential complications but indicating these are irresolvable; or endeavouring to work out a resolution. As Traps states "translation does not simply copy but actively creates" (2009:144). She goes on to suggest "The translator is not merely an observer [then] but an active maker of meaning and frequently its final arbiter" (Traps, 2009:145). Hence the role of the translator can always be problematic (Traps, 2009). How safeguards were put in place to demonstrate how sufficient attention was paid to potential problems will now be discussed.

3.11.2 Spontaneity.

Raval and Smith (2003) undertook an empirical study to determine why the anecdotally reported apprehensions when working with interpreters arose. They discovered that some of their practitioners found that using interpreters took away the immediacy of communication, as the researchers had to wait for the interpreters to direct their questions to the participants and then wait for the participants' responses to be translated back to them. Within my study, the interviewer was working from a set of semi-structured questions, which had been translated in a joint meeting between me, my bilingual mentor at AISM, and the interviewer. Therefore the conversation flowed freely

between the participants and the interviewer and loss of spontaneity and momentum in communication was not a concern for my interviews, as there was not a third party there (i.e. an interpreter) to disrupt the natural flow of conversation. However, although my language ability allowed me to understand the basics of the conversation, I was not privy to the specific dialogue until the interviews had been transcribed and translated. These issues will be considered within the discussion chapter, as regards my role in the interviews.

3.11.3 Accuracy.

I am aware that “linguistic and social context of concepts must be made visible and problematized in the process of translation” (Alvanoudi, 2009:20) and that as a non-speaker of Italian conducting my research with Italian women I had “a responsibility to maintain the integrity and credibility of translated qualitative data” (Squires, 2008:266). I therefore needed to demonstrate the accuracy of the translations and I used the method of back translation, which is recommended to validate the translated text (Esposito, 2001). Despite the fact that back translation is based on a positivist approach, assuming one truth, one experience of social reality, by adopting a ‘right or wrong’ approach to determine the correctness of language, its use has not been significantly challenged within the discourse on translation (Temple, 2002). In my study three interviews were back translated, one to represent each of the three groups of participants. This back translation was undertaken by a native Italian speaker who had a good command of written and spoken English. This person was otherwise not involved in my study and provided a service to provide these back translations only. Very few minor discrepancies between the language used in the original translation and the back translation were noted and these were discussed with the interviewer, to ensure that my participants’

words had not been misrepresented. In this way, I ensured as far as was practically possible, the accuracy of the translator in translating the Italian spoken language into written English.

It is important that the use of back translation is considered as an addendum to other safeguards which were applied to ensuring the accuracy of the data. As Temple suggests “The choice of suitable word or concept equivalence is integral to interpretation/translation and is rooted in the experience of the translator/interpreter” (2006:13) which she suggests is irresolvable by back translation. Temple argues that one of the issues with using back translation and ensuring accurate translation through use of professional interpreters is that there will also be a choice of words that the translator needs to choose from, which can have different connotations across the languages (2006). She also draws on research which suggests that the reader or listener of the text is also active in constructing its meaning (Temple 2006). Therefore, in addition to using back translation, I also followed up on some of the themes that arose in the first interviews in the second interviews, which were conducted with a sub-sample of my participants. A comment at the end of one of these follow up interviews gave some reassurance that my interpretations of the first interviews had understood the words of my participants:

“It was lovely and I see that you have truly read and listened again.....” (Sonia).

As well as enabling me to further pursue some issues that were raised in the first interviews, following up on some themes identified from the first interviews, also facilitated a method of “member checking” (Seidman, 1991) or respondent validation. This further promoted an empowerment approach to my research, as it gave my participants the opportunity to feedback on my initial analysis of the issues they raised during their interview. Furthermore, there have been arguments presented that non-

disabled people should not conduct disability research, because they will analyse findings based on a non-disabled interpretation (Morris, 1993a). Therefore through undertaking this member checking, I made myself as a researcher more accountable to my participants and by sharing the findings with my participants, I increased the trustworthiness and credibility (Seidman, 1991) of the data. These methods further ensured that the words of my participants were not lost in the translation process and that I was accurately representing their views.

Another issue identified by Raval and Smith (2003) was around the interpreter summarising information and/or not translating the information exactly. However, as Temple recognises, “changing language involves more than a simple change of words” (2008:355); translations need to be meaning-based, rather than literal word for word translations (Esposito, 2001; Berman & Tyyskä, 2010). Temple (2006) also cautions against the tendency of researchers to produce “neat and tidy” accounts that “foreignize” text to fit with the expectations of the reader, for example by adjusting the language to make it grammatically correct. This could occur if the researcher overlooked the importance of ensuring the translation is meaning-based, and the researcher needs to recognise “that neatness does not imply ‘good’ research” (Temple, 2006:17). Alvanoudi also states that as “words carry socially and culturally defined meanings which orient speakers towards different perceptions of the world, then these meanings must be considered and made visible in translation processes” (2009:23). When concerns are expressed in the literature regarding cross- language studies, these are frequently related to the interviewer/interviewee relationship and how the interviewer may distort or misrepresent the participants’ responses (Edwards, 1998). However, in my study, the

interviewer conducted the interviews wholly in Italian, with complete dialogue being audio recorded and the translation occurring post interview. The audio recordings were transcribed verbatim and then were translated into English by an independent translator. As she was independent of the research study, she had no vested interest in the study findings and thereby no conceivable incentive to move away from the “unadulterated truth” of the participants words (Edwards, 1998:201). Aside from her professional commitment to ensuring the accuracy of the interview data, the translator also had a personal interest in the study (which is discussed below), and therefore it was foreseen that she would be sufficiently motivated to ensure the accuracy of her translation. In this way, by having a separate person to conduct the interviews and to translate them, it allowed transparency in what was asked and what the responses were, to avoid neither the interviewer nor the translator shifting into an advocacy role, as this can be problematic (Raval & Smith, 2003). Other measures in attempting to ensure the accuracy of the data were also put in place.

With regards to the translation of the interviews, I had access to both the Italian and English scripts and was able to cross reference any words or terminology used. I also involved the interviewer in discussing with her any questions I had about accurate translation of the text. One example of this was when the translator had transcribed the word “aborto”, which means both abortion and miscarriage. The translator had assumed, because of her previous exposure to the Italian culture that the woman was referring to having had miscarriages. However, the surrounding discourse, when the participant was speaking about her husband, was not consistent with this. On discussing this issue with the interviewer, it was discovered that the woman had had one miscarriage and one abortion. This information was fed back to the translator and I reinforced that in the

future if any words had more than one meaning, or if she was deliberating on the meaning of words, that she be open about this, and either put both words into the text, or contact me to confer on which was the most likely option in the context of the conversation. Following this discussion, the translator became more forthcoming in adding notes to the scripts, to enable me to identify when dilemmas arose. In this way, the translator then demonstrated a more dynamic role within the construction of the dialogue. As Raval and Smith recognise, the issue of contextual understanding (2003:23) is most pertinent to the translation process. I also worked to ensure accuracy of the translations by listening to a number of the recordings or part thereof, to check the accuracy of the Italian scripts. Furthermore, with regards to the feedback process, the participants were offered copies of their own recording and transcriptions, which many then requested. Had there been inaccuracies within these, it would be hoped that the participants may have fed this back, due to the openness proffered within the researcher/participant relationship. The interviewer also took an active role in comparing the back translations and provided me with both verbal and written comments on any minor discrepancies that she found. These were grammatical errors, rather than fundamentally altering the meaning of the text.

In terms of ensuring the accuracy of the interviewer's translation, as mentioned above, the interview questions were initially translated in a meeting. Any subsequent question changes were negotiated between the interviewer and myself as part of our regular discussions regarding the interviews. The role of the interviewer in translation also involved her taking more of a corroborating role in relation to translation of the interviews, as described above.

3.11.4 Familiarity with the Context.

A further concern from Raval and Smith's study was around the interpreters being unfamiliar with the clinical context and thereby having difficulties accurately interpreting the questions (Raval & Smith, 2003). Larkin et al (2007) also felt that one weakness of their study was that their translators were unfamiliar with the concepts under investigation, which may have impacted on the mutual reciprocity between the translator and the researcher. As mentioned earlier, the interviewer was familiar with the clinical context as she was working with people with MS on a day to day basis, and I spent time discussing the purposes of the study with the interviewer prior to commencing the interviews. For the translator, as her mother had MS, this not only motivated her to participate in the study, but also facilitated her familiarisation with the clinical context. I was aware of factors such as this when in the process of choosing the right translator to undertake the work.

3.12 Choice of Translator.

In considering the role of the translator, I was attentive to the potential for them to have an impact on the data, to take an epistemological role, and to take on a role of data generator (Squires, 2008). In selecting the translator I was mindful that "How people present themselves and how they are perceived is affected by the languages they use. Who translates matters" (Temple, 2008:362). Esposito (2001) suggests the role of a translator is to "process the vocabulary and grammatical structure of the words while considering the individual situation and the overall context of the SL (source language). The interpreter then conceptualises the meaning and, using vocabulary and grammatical

structure appropriate for the TL (target language), reconstructs the meaning of the statement in a new cultural context” (2001:570).

Finding a translator who had both language proficiency *and* cultural awareness was therefore necessary (Larkin et al., 2007) when conducting my research study. There is a widespread debate within social science research of the influence of social factors such as the ethnicity, gender, age, and sexuality of the researcher (Temple, 2002). If these factors are relevant for the researcher, then they are also applicable to others involved in the research, such as translators (Temple, 2002), or for my study, the interviewer and the translator. For my study, most of these factors could be not pre-empted, as the interviewer was allocated to work with me by AISM, and these social factors were not felt appropriate to question the translator about. However, the fact that both the translator and interviewer were women may have assisted the research relationships. How such issues impact on power in relationships between the researcher and participants are much discussed topics by feminist researchers with regards to power within interviews (Garg, 2005) and consideration as to the power dynamics within my study will be considered later.

Squires (2008) describes the potential difficulties with using a lay rather than a professional translator and the vital importance of the translator considering not only the structure of the words used, but also the context and culture in which the words were said. Corresponding to the budget restrictions acknowledged by Squires (2008) in recruiting a professional translator, it was necessary to consider the feasibility of employing a non-professional translator to assist me with my study. With this in mind, in determining the suitability of the translator, I referred to Squire’s synthesis of

recommendations of the qualitative research methods literature (2008). Using linguists' hierarchy of language competence, Squires suggests that translators must have a minimum level of sociolinguistic competence. Squires also draws on recommendations by Twinn (1997) that a single translator is used for all written translations, to ensure consistency and "improved conceptual congruency" (Squires, 2008:270) throughout the translation process. However, in selecting a translator, I was also aware that the person who was translating the words of my participants would need to choose words to reflect the meaning of the text, which would be influenced by their experiences with the language involved (Temple, 2008). I therefore chose a translator who not only had a high level of technical competence with the language, but also had experience of the lived culture of Italy and had experience of translating for Italian women. The chosen translator holds a BA in Italian and Linguistics, has three Italian language diplomas, a full advanced diploma of the Italian Language and at the time of the study was completing an MA in Interpreting and Translation at an English University. Therefore I felt that although she was not a practicing professional translator, she had sufficient academic qualification to undertake the required translation.

Though Raval and Smith's (2003) study concerned the experience of mental health practitioners using interpreters to assist with therapeutic work, the examples they give of good practice can also be applied to the research process and they suggest abiding by ethical and good practice guidelines helps to alleviate many of the potential difficulties (Ravel & Smith, 2003). They propose the practitioner (or researcher) should allow adequate time to brief and debrief the interpreter, which may help to resolve the role ambiguity for the participants and interpreters that they found.

3.13 Briefing and Debriefing.

At the early stages of my research, prior to conducting the Italian pilot interview, a briefing meeting was held between myself, the interviewer and my mentor at the AISM. Meeting with the interpreter prior to carrying out the interviews is recommended by a number of researchers (Raval & Smith 2003; Wallin & Ahlström, 2006). The purpose of this briefing meeting was to inform the interviewer about the existing literature, discuss my research aims and to review the wording of the interview schedule. Addressing issues of translation only when at the stage of analysing the data is insufficient and matters concerning rigour are equally applicable to the whole process, including the formation of the interview and the interview questions (Larkin et al., 2007). Although the interviews were conducted by a native Italian speaker, who had a good clinical understanding of the participants' condition, she was not required to provide an interpreter service within the interviews, as the interviews were conducted in Italian and then transcribed and subsequently translated by the translator described above. However, the interviewer did assist in an interpreter role by clarifying any points I heard during the interviews. For example, when I understood in an interview that a woman was talking about how she could not access her children's school, at the end of the interview I would ask the interviewer "when she spoke about not being able to get to her children's school, can you ask her how she felt about that?". Then the interviewer posed this question in Italian to the participant to enable a deeper understanding about the woman's feelings about what she had told us. To avoid my needing to intervene in this way as much as possible, it was vital that the interviewer had an understanding of the interview questions, in order to provide the appropriate prompts herself and know how to facilitate my participants' expanding on their responses.

To facilitate this, the above briefing meeting took place, and proved to be invaluable, as not only did it enable me to instigate a working relationship with the interviewer, it also identified that revisions to my interview schedule were necessary. Drawing on recommendations by Squires (2008) I had attempted to simplify the questions to facilitate the translation process. However through doing this, the questions unintentionally came across as being too formal and insensitive. Furthermore, from a translation perspective, potential misinterpretation of terms such as “help” and “support”, with disparate meanings in Italian and English became apparent. It was imperative that the interview schedule and questions accurately reflected the meaning or construct of language within the culture of my participants (Lange, 2002). As Raval and Smith’s (2003) study found, there is a need to interpret the culture as well as the words, to be bicultural as well as bilingual. The wording was therefore clarified and a pilot interview, using the translated interview questions with an Italian disabled woman was conducted, to enhance the credibility of my future findings (Squires, 2008). As the interviews progressed and the interview schedule developed, I added some additional prompting questions, which the interviewer read, we discussed and then she translated into Italian.

In terms of my working relationship with the translator, I spent some time before the start of the interviews briefing her on the topic and the current literature and the methodological implications for her role. Having grown up with a mother with MS she already had some insight into the nature of the condition, which I felt would be helpful in terms of understanding of terminology and in empathy towards my participants, as well as overcoming the issues with contextual awareness (Raval & Smith, 2003) that other translators may not have had. I also had specified to the translator that any possible

phrases of terms which were difficult to match with English terminology should be transparent and possible variations in the translation were inserted into the transcribed and translated transcriptions. Due to the fact that the translator was based in England and I was based in Italy, this consultation was done by email exchange, rather than face-to-face, as it was with the interviewer.

This process of consultation with the interpreter or translator is recommended by Raval and Smith who state that “The inevitable changes that occur in translation and the need to simplify questions and the language used can be considered necessary for meaningful and culturally appropriate communication to take place” (2003:23). Through this initial communication, I was ensuring that the language used in my interview questions was sensitive to the culture of my participants. Once I had briefed the interviewer and translator, I had to be confident that they would both fulfil their roles, therefore trust in both the interviewer and translator was significant for me as the researcher.

3.14 Trust.

An important issue found in Raval and Smith’s (2003) study was that of trust. They suggest that this was predominantly due to the practitioner not knowing what was being said between the interpreter and the family, and how accurate the interpreter was being in translating the information. As indicated above, I quickly began to understand the questions being posed and recognise a significant amount of the subsequent dialogue. Not only did this enable me to maintain an active role in the interviews, despite not actually participating in the main dialogue, it also assisted me in trusting the interviewer to ask the correct questions. Furthermore, as the whole interview was recorded, any

modifications in the questioning would have been elucidated in the scripts, though when this did occur, it was found to be entirely appropriate to the context of the interview dialogue.

My trust in the translations was increased by the use of back translations and through my increasing awareness of the conversations that occurred during the interviews. I was therefore able to recognise that when the translations were returned to me, that the information in them reflected my understanding of the discussion that took place at the time. My trust in the translator also increased with her increasingly active role, which is addressed within the discussion chapter.

My trust in the interviewer and translator was established through the processes described above. I was mindful of a study conducted by Hsieh et al (2010), which investigated the challenges to effective collaboration between health care providers (or practitioners) and interpreters to establish an empirically based framework of provider-interpreter trust. They identified four dimensions of the trust framework: interpreter competence, shared goals, professional boundaries and established patterns of collaboration (Hsieh et al., 2010). The above discussion reflects how these dimensions were addressed, but these issues will also be reflected on further within the discussion chapter.

3.15 Summary of Roles.

To promote an effective working relationship between the interpreter and researcher, the same interpreter should be used throughout (Raval & Smith, 2003; Wallin & Ahlström,

2006). Within my study, both the interviewer and translator remained consistent during the course of the study and effective working relationships were established. It is suggested that defining roles and goals should be undertaken in order to avoid role ambiguity and to assist in developing an effective working alliance (Raval & Smith, 2003). The above discussion reflects on how the relationships and establishment of roles and goals were managed in my study. This was essential as I had a responsibility to put into place all possible safeguards to ensure that my participants' words were translated as accurately as possible. The following sections will further explain the conduct of my study.

3.16 Sampling.

As an English speaker intending to conduct a study in Italy, it was necessary for me to identify a means of recruiting participants, due to my unfamiliarity with the language and setting of my fieldwork. Through a contact who worked for the AISM, I was able to use this service to act as gatekeepers (Seidman, 1991), as a means of accessing potential participants. The framework I selected to gain a research sample needed to be consistent with the qualitative paradigm adopted (Smith et al., 2011) and I used purposive sampling to identify my potential participants. This sampling framework is commonly used in qualitative research (Green & Thorogood, 2005) and enabled me to find participants who had experience of the phenomena of the study (Starks & Trinidad, 2007), that is, mothers who were living with MS. IPA studies should try to ensure the sample group is as homogenous as possible (Smith et al., 2009; Clarke, 2009; Cronin-Davis et al., 2009), to enable exploration of a phenomena within a specific group, clients with a particular diagnosis serving to provide a suitable example (Clarke, 2009). Although I acknowledged that looking at parenting in relation to a specific impairment perpetuates the medical model view of disability (Olsen & Clarke, 2003), in order to provide a lens through which

to examine disability and motherhood and for the practical considerations of conducting fieldwork in another country, my study focused on the experiences of women from this impairment specific group. However, my study attempted to distance itself from taking a medicalised view of disability, by considering the model of disability proposed by disabled people themselves, as described earlier. Despite the necessity to include a medical measurement (an impairment scale) to identify and recruit my participants (as outlined in section 2.11.2), the findings will be presented within a social model of disability framework.

IPA studies vary in numbers of participants, with ten participants being the optimum recommended maximum sample size (Smith et al., 1999), but fifteen participants being the mean number within the IPA literature base collectively (Reid et al., 2005). My sample therefore was at the upper end of typical sample sizes used with IPA studies, being sixteen in number, including the data collected in the pilot interview. Having a sample of this size enabled me to examine in some detail convergence and divergence of experience within the sample (Smith et al., 2009).

Moreover, my study participants reflected a diversity of those who had children after they were diagnosed with MS, and those who already had children when they were diagnosed, although these factors were not specified when recruiting the sample. This is relevant in considering the potential social impact of impairment upon activities and role performance, as in work and/or motherhood (Harrison & Stuifbergen, 2005). In other words, the experiences of women who had children after their diagnosis could be different to those who were diagnosed when they already had their families; in a similar way to the experiences of those who age *with* impairments from childhood may be

different than for women who age *into* impairments later in life (Verbrugge & Yang, 2002).

An IPA study reflects both the subjective, unique aspects of experience and the common, shared aspects, which are constructed by external forces within a culture and subculture (Shaw, 2001). This was relevant to my study both in considering the external influences of the Italian culture and the subcultures of motherhood, womanhood and disability within that. A study focusing on the occupational experiences of people with MS, suggests that studies should consider the disease duration, type of MS and age of participants, to allow for a greater insight into how these variables impact on occupational engagement (Lexell et al., 2009). These factors were not taken into account in the recruitment process for my study, as it was felt this perpetuated a medicalised view of the women's lives. However, the way that different levels of impairment impacted on the women's experiences was taken into account in the analysis. Moreover, in order to consider a range of experience and possible disease related variation (Lexell et al., 2009), five women were recruited from three impairment level groups. In this way, through selecting women who were at different stages of their MS, I hoped to capture a variety of experience, which may or may not be influenced by disease specific factors. Furthermore by broadening out the criteria, to consider a spectrum of experience, it was hoped that the findings would offer wider transferability and relevance to other women with impairments and those providing services and support to them.

Taking these factors into account, the following inclusion criteria were applied:

- The participants were known to the AISM service.
- The participants were women who had a diagnosis of MS.
- The participants were a mother to at least one child aged 18 years or younger, who was still living at home.

Five women were recruited from the following groups:

Group 1 – women with a diagnosis of MS, who had some level of impairment which impacted on their everyday function. This group incorporated women who were still mobile without aids, but were borderline for needing aids to assist them with everyday tasks.

Group 2 – women who had a greater degree of physical impairment, which regularly impacted on their everyday function.

Group 3 – women who were severely physically impaired and were regular wheelchair users.

In order to assist the recruiter in approaching potential participants, the above groups were specified by using the Expanded Disability Status Scale (EDSS), which is one of the most established and utilised assessment tools for people with MS (National MS Society, 2013) and has recognised categories of recording information about clients on the AISM database. The groups were therefore further defined using this measure, with the women in group 1 being those at level 4.5, 5 or 5.5 on the EDSS, group 2 being at level 6 or 6.5 and group 3 at level 7, 7.5 or 8. Due to the necessity of my using a gatekeeper to access my participants (Seidman, 1991), I used opportunistic purposive sampling (Smith et al., 2011) and relied on colleagues within AISM to assist with recruitment to my study. A

psychologist from AISM and the occupational therapist who assisted with my study, worked together to identify potential participants from the AISM database. These women were then contacted by phone and if they expressed an interest, they were sent an information sheet and a consent form, copies of which can be found in appendices 1 and 2. These were written up by myself in English, translated by the external translator, and then checked by a third party bilingual native Italian speaker for accuracy. When these had been sent out to potential participants a follow up phone call was made to confirm their interest in the study and to set up an appointment for the interview. At the beginning of each interview it was confirmed that the participant had received and understood the information sheet and the consent form was signed by the participant and collated by myself.

The table below outlines the profile of my participants. Silvia was the woman who participated in the pilot interview, whose story was included in the analysis. Pseudonyms are used for all the participants.

3.17 The Profile of my Participants.

Interview	Group	Aware of diagnosis prior to pregnancy	Children's age and gender	Marital status
Silvia	1	Yes	Boy age 16, Girl age 14	Married
Leona	1	No	Boy age 10	Second marriage
Sonia	1	Yes	Girl age 6	Married
Erica	1	Yes	Twins boys age 8	Married
Rosa	1	Yes	Girl 12 & Boy age 8	Married
Delia	1	No	Boy age 16	Married
Laura	2	Yes	Boy age 7	Married

Maria	2	No	Boy age 8, Girl age 15	Married
Julie	2	No	Girl age 10	Married
Patrizia	2	No	Boy age 15 & Girl (adult)	Married
Ottavia	2	No	Two girls age 9 & 5	Married
Alessandra	3	Yes	Girl age 2	Married
Francesca	3	No	Girl age 16	Separated
Elisa	3	Yes	Boy age 11	Married
Cristina	3	No	Boy (24) & Girls age (21) & 12	Married
Fiorella	3	Yes	Girl age 14	Separated

3.18 Data Collection.

As identified earlier, the data for my study was collected through the use of face-to-face interviews. I recognised the value of pre-testing the interview questions through piloting (Larkin et al., 2007) and a pilot interview was first conducted with an English speaking mother with MS, in England, to ascertain the pertinence of the interview questions. These were found to be appropriate and the interview schedule remained unchanged. Then a second pilot interview, using the Italian interviewer and translator, was undertaken with an Italian mother with MS, to pre-test the logistics of the interview process and the cultural applicability of the questions. Other than some practical issues with turnaround time for the transcription and translation, and mishearing due to background noise, the set-up of this interview arrangement worked satisfactorily. As the data collected in the Italian pilot interview was an in-depth discussion of the experience of being a disabled mother in Italian society, I decided to include this data in my analysis.

Following the pilot interviews, initial interviews were conducted with fifteen Italian women. I then conducted second interviews with seven participants, in part to “engage in another conversation with them about my interpretation – to have a literal interpretative dialogue about my virtual interpretative dialogue” (Smith, 2007:6). That is, the interpretation I had applied to the words of my participants’ first interviews. As well as the second interviews enabling checking of the interpretation from the first interviews, they also served to allow follow up for some specific issues for the women that had arisen in the first interviews. The interview schedules for the first interviews and an example of the schedule for the second interviews are included in Appendix 5 and 6.

3.19 Interview Questions.

As stated above, a semi-structured interview format was selected for my study. This was in part because this form of interview is frequently used and endorsed for IPA studies (Cronin-Davis et al., 2009; Clarke, 2009), and using a narrative approach to data collection supports an empowerment approach to research. However, it was also influenced by the fact that I was conducting my fieldwork in a language other than my own. Selecting a semi-structured question design allowed me to ensure that the interviewer understood the specific questions, whilst allowing the participants to add to them by giving fuller accounts of their experiences in relation to the questions asked. Use of semi-structured questions enabled a balance between flexibility for the participants’ responses and preventing the interviewer from straying from the context of the interview focus. The questions were informed by my literature review and were based on the themes arising from the existing research on disability and parenting, but the questions were also

strongly linked to the aims of my research, and all questions were open-ended. My research questions are stated in section 2.14 and a copy of the questions is in Appendix 5.

By using open-ended questions, further elaboration by the participants was facilitated. Furthermore, having an awareness of the translated questions beforehand enabled me to listen out for the questions being posed by the interviewer and hear key words and observe any non-verbal communication that accompanied the responses of the participants. As the interviews progressed and my language skills increased, it also enabled me to prompt the interviewer to explore areas in more depth when issues were raised by the participants. However, my role in the interviews was mainly as an observer of communication. As Riessman (1993) states “how something is said is as important as what is said” (in Temple, 2005:6).

Initially it had been my intention to take notes describing any emotive issues expressed within the interviews and any general issues such as the participants’ ability to retrieve information. This is useful when undertaking interviews to assist with interpreting the data (Fade, 2004). However, taking notes felt intrusive and prevented the participants in making eye contact and forming a connection with me in the interviews. Instead, I relied on the translator inserting comments and pointers within the transcripts, to assist me in recalling how the women expressed emotion during the interviews.

When conducting the interviews, it became evident that my participants “were able to vividly recall and thus richly describe (their) actual experiences almost as if they were re-living them again” (Wilding, 2011). In order to facilitate this open conversation on their experiences as disabled mothers, thought needed to be given to the questions that would

be posed in the interviews to elicit such memories. The following section will outline the guiding questions of my study, to demonstrate the foundations on which the interview questions were formulated.

3.20 The Study Questions.

The central guiding question of my study was:

- “How do disabled women experience their lives as mothers in Italy?”

To illuminate this issue question, topic questions were also formulated to assist. These were:

- What factors have influenced how mothers have maintained their role since the onset of their impairment; have they needed support and if so, how do they view that support?
- How do external barriers, such as environmental, societal or attitudinal, impact on the women’s experience of being a disabled mother?”

A substantial part of the first topic question reflected how those women who had needed support had been able to retain their role as mothers. This is important as when considering independent living “The real point is whether these means deliver the ends – which is the protection and promotion of human rights” (Morris, 2001:28). In this way, I considered whether the support the women received facilitated their human right to be a parent and whether the help they received enabled them in their role, or led to them feeling that they were being “cared for” and had lost control in their role as a mother. These issues of “choice and control” underline the definition of independent living defined by the disabled people’s movement (Morris, 2011) and illuminate issues of

potential oppression for my participants as women. This question was also influenced by the literature on disability and parenting, which considers the involvement of professionals, the role of formal support and the influence of family members in the lives of disabled people.

Furthermore the reason for exploring this topic question of how women viewed their support, was to tackle the question posed by Jenny Morris as to how one defines “taking care” and whether it is possible to both be “dependent” on others and to have one’s human and civil rights fully recognised” (Morris, 2001:24/25). Again, this fits with the principles of the disabled people’s movement which states “Independence is not about doing everything for yourself but about having control over how help is provided” Morris, 2001:15). How my participants viewed their care highlighted how much control they considered they had over their support.

The second topic question related to other issues raised in the literature around the socially constructed barriers which affect the lives of disabled parents. This was considered in a broad sense, with reflections on the wider socio-cultural influences that could contribute to these barriers. The following section will detail the practicalities of how the interview data was analysed, to show how the findings arose.

3.21 Steps of Analysis.

Smith et al’s (2009) step by step guide suggests six stages to the analytic process. These are: reading and rereading, initial noting, developing emergent themes, searching for connections across emergent themes, moving on to the next case and finally looking for

patterns across cases. As a novice researcher, I considered it beneficial to have a structured approach to analysis, and I chose to follow Smith et al's six steps to analysis. Analogous to the first step of analysis suggested by Biggerstaff and Thompson (2008), Smith et al (2009) propose the first stage involves reading and re-reading the transcripts. I undertook this process by reading the English translated transcripts, but also by reading the Italian transcripts if I was struck by the use of language, to find the original wording that had been used. One example of this was the use of the word "suffer". In first reading this in the English transcript, I was struck by the intensity of this description. Returning to the Italian transcript, I was able to confirm that the original wording used, "soffrire" did indeed depict that the participant was referring to a description of suffering. By reading and re-reading the English transcripts and being able to cross reference with the Italian transcripts, I was able to begin to immerse myself in the data and to actively engage with it (Smith et al., 2009).

The most detailed step follows, with the researcher examining and making notes on the semantic content and language of the data (Smith et al., 2009). This involves making initial notes and comments on the data and ensures an increasing familiarity with the transcripts (Smith et al., 2009). Smith et al (2009) point out that there are no rules about what to comment on, but the aim is to produce comprehensive and detailed notes and comments on the data. I embarked on this stage by highlighting words and sentences in the transcripts that seemed of interest and making notes, often questions to myself, in the margins of the pages. To avoid my lapsing into superficial reading, therein commenting just on what I was expecting to see in the data (Smith et al., 2009), I read the scripts from beginning to end and then returned to them at different points and different times, to ensure that I was fully engaged in the reading process. I used different coloured

pens to make my comments, and avoided as far as possible reading the previous comments I had made each time. Smith et al suggest three types of applicable comments; descriptive, linguistic and conceptual. Within the descriptive comments, I noted words and phrases and took things “at face value” (Smith et al., 2009:84). The way I addressed linguistic comments has been highlighted above, by comparing the English and Italian wording. I also recognised laughter, hesitancy and other functional aspects of the language (Smith et al., 2009) which was aided by the translator having written in comments within the transcripts to depict laughter, tears and such like, that she picked up from the recordings. These comments assisted me in recalling the participants’ emotions as they occurred at the time of the interviews. I was also able to listen to the original Italian recordings, to aid my understanding of the depth of emotions portrayed. My noting of questions to myself in the transcript margins, as described above, fulfilled the conceptual comments component of this stage of the analysis. As Smith et al (2009) indicate, this stage also involved an amount of reflection on my part, through drawing on my experiential and professional knowledge. This assists with the commencement of the interpretative element of the analysis, through acknowledging one’s own preconceptions.

The next stage of developing emerging themes aims to reduce the volume of data, whilst maintaining the level of complexity, by looking for interrelationships, links and configurations from the initial notes. This shifts the analysis from working with the transcripts themselves, to working with the initial notes (Smith et al., 2009). I undertook this element of the analysis by using post-it notes. I transferred notes and quotes from the transcripts onto the post-it notes and then placed them onto a large surface individually. I then started to group them into larger related clusters, looking for emerging themes (see Appendix 7). This process was repeated from scratch, disassembling and

then replacing the post it notes, to see if similar groupings emerged. The focus of IPA on “convergence and divergence within a particular group’s experience of a phenomenon naturally requires comparisons at the individual level (comparing case to case)” (Hefferon & Gil-Rodriguez, 2011:757).

The above three steps were then repeated for each transcript, to allow me to move from case to case. In considering each subsequent case, I was mindful to bracket the ideas which had emerged from the previous transcript analysis and consider each new transcript in its own right. This was achieved by spacing out the time frame between reading and rereading each script and doing the initial coding. Although Smith et al suggest that moving from case to case is done after the stage of looking for connections across themes, they also recognise that when working with larger samples, one can delay “the search for patterns and connections until one is examining all the cases together” (2009:106). This was the case for my study, when the stages of reading and looking for emerging themes was undertaken on all the transcripts, prior to searching for connections across the themes.

The next stage was therefore to look for connections across themes and Smith et al (2009) suggest a number of ways of doing this. This stage involves developing broader ranging ‘super-ordinate’ themes. This was done by using abstraction, that is “putting like with like and developing a new name for the cluster” (Smith et al., 2009:96). I did this by grouping the post-it notes further, through identifying links between the themes. I combined this with polarisation, looking for “oppositional relationships” (Smith et al., 2009:97), where views appeared to contrast; and numeration, in looking for the frequency in which emerging themes arose within the transcripts.

The final stage is to look for patterns across cases. This is achieved by reviewing the themes and can lead to relabeling of themes. This is often presented in the form of a table, to illustrate how themes sit within the super-ordinate themes and quotes from the transcripts are used to substantiate these. As well as using representative sample quotes to corroborate the themes, I also went back to each interview script and produced a table which demonstrated the relevant quotes from each woman in relation to the identified themes. These last two steps are similar to stages three and four of Biggerstaff and Thompson's (2008) guidelines to analysis, which propose clustering the themes together into groups, with the final stage entailing producing a summary table of organised themes. These tables are detailed within the analysis chapters. Having undertaken these steps to analysis, each superordinate and sub-theme was written up into narrative accounts, which allowed significant depth of the description of my participants' accounts (Fade, 2004). Links to the existing literature were then amalgamated into this write up, as appropriate (Fade, 2004) within the discussion chapter. The following chapters will now explore the themes arising from the analysis, resulting from the steps taken above.

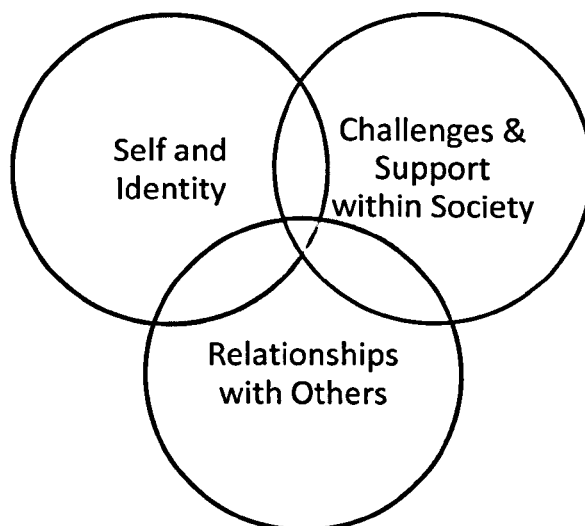
Chapter 4 – The Analysis:

4.1 Introduction.

*“I’ve done everything that the other mothers have, I haven’t done anything less!
Even if I’ve forced myself, perhaps arriving home exhausted.” (Delia).*

The above quote from one of the participants, Delia, demonstrates the strength women showed in endeavouring to fulfil their role as mothers. The women’s stories about their lives as disabled mothers were influenced by many factors, including their own feelings, how other people interacted with them, and what barriers they faced within society. From the women’s narratives about their lives, a number of sub-themes were identified. These themes were then grouped into three overarching superordinate themes, which were ‘*Self and Identity*’; ‘*Relationships with Others*’; and ‘*Challenges and Support within Society*’.

Figure 4.1.1 The Three Superordinate Themes.



As shown in the above diagram, these superordinate themes had overlapping elements, but there were also links between the sub-themes of the three superordinate themes. The links between the sub-themes are demonstrated within the text of the chapters, by the use of brackets and signposting to the relevant section, for example (see 5.6 'stigma and disclosure'). These links will also be referred to within the discussion chapter.

The following analysis reflects the views of the sixteen women interviewed and considers the similarities and differences in their interviews. The analysis will reveal how these superordinate themes were identified, by discussing the emergent sub-themes, and how these linked to the narratives of the interviews. In line with IPA, quotes are used to substantiate the findings and some additional information about the women will be given within the chapters or after each quote, where relevant. The analysis is divided into three chapters, each one discussing one of the above superordinate themes. At the beginning of each chapter, the superordinate theme and underlying sub-themes will be represented in diagrammatic format, then within each chapter, each sub-theme will be considered in turn, as defined in the figures, rather than in any hierarchical order.

4.2 The Participants.

Although some basic information about the profiles of the participants has been outlined in section 3.17, a more contextualised pen picture of each of the women will now be given.

Silvia was married and aged 45 years. She knew her diagnosis prior to becoming pregnant as she was diagnosed at the age of 26. She had a 16 year old son and a 14 year old daughter.

Sonia was married and was 47 years of age. She was diagnosed with MS in her mid-twenties. Sonia had a daughter aged 6 and worked full time.

Erica was married and had twin boys aged eight. She was 40 years old and was diagnosed in her late twenties. She was still working at the time of our interview.

Leona had been married twice and had a 10 year old son from her first marriage, who lived with her and her second husband. She was 35 years of age and had symptoms of MS since the age of 18, but was diagnosed with demyelinating disease¹. She was given the diagnosis of MS during her pregnancy when she was 25 years old.

Delia was married, aged 42 and had a son aged 16. She had symptoms since 1989 but had been diagnosed with demyelinating syndrome. Delia was given the diagnosis of MS during her pregnancy, when she had a relapse.

Rosa was married and had two children, a daughter aged 12 and a son aged 8. She was diagnosed with MS when she was 20 years old. She had worked up until her children were a few years old.

Maria was married and had a daughter aged 15 and a son aged 8. She had had MS since the age of 18 but was not diagnosed until after the birth of her second child, therefore did not know her diagnosis when she had her children. She was married and had previously worked, but was no longer working when we met her.

Julie was 43 years old, married and had a 10 year old daughter. She was diagnosed when her daughter was a year old, but had some symptoms prior to this and was diagnosed

¹ demyelinating disease encompasses any condition characterised by damage to the myelin sheaths of nerves.

with demyelinating syndrome. Julie had worked for many years, but had finished working two years prior to the time of our interview.

Laura was married and had a son aged 7. She was 34 years of age and was diagnosed with MS when she was 23. Laura had worked up until her pregnancy.

Patrizia was married and had two children, a daughter older than 18 who still lived at home, and a son aged 15. Patrizia was diagnosed with MS when her son was two years of age.

Ottavia was married and 39 years old. She had two daughters aged 9 and 5. Following an exacerbation of some minor symptoms, Ottavia was diagnosed with MS when her younger child was a month old. She had previously worked but was no longer working at the time of our interview.

Francesca was 51 years old, married and had a daughter aged 16. She was not aware of her diagnosis when she had her daughter, but was diagnosed when her daughter was around the age of 7 or 8. Francesca previously worked but had finished working two years before we met her.

Elisa was 43 years old, married and had a son aged 11. She knew her diagnosis when she became pregnant and had continued to work after her son was born, but had finished working by the time we met her.

Alessandra was married and had a daughter aged 2. She was 38 years old and had been diagnosed with MS when she was 23. She had worked up until around a year prior to our interview.

Cristina was married and had a daughter aged 12 and two grown up children who were still living at home. Cristina had had symptoms of MS for ten years prior to being diagnosed, which was confirmed when her youngest child was aged 6. Cristina did some volunteer work, but was not in paid employment.

Fiorella was divorced and had a partner but he did not live with her. She had a daughter aged 14 and knew her diagnosis when she became pregnant. *Fiorella* had formally worked but was no longer working at the time of our interview.

Following the initial interviews, seven women were interviewed for a second time. These women were Silvia and Sonia from group 1; Maria, Ottavia and Patrizia from group 2; and Alessandra and Elisa from group 3. Therefore, a more or less equal number of participants were chosen for a second interview from each group, with an additional participant from the middle group. These women were specifically selected due to the depth of information they shared during the first round of interviews and because they reflected a balance between the demographic information, such as the ages of their children, whether or not they knew their diagnosis prior to becoming pregnant, and the level of their impairment. Within the analysis, an attempt has been made to represent each woman's views on an equitable basis. However, this was limited by the level of information the women chose to share about their experiences and generally, the more impaired the women were, the more in-depth the interviews were. There is therefore more of a representation of their voices, than the women who were less functionally affected by their MS. There is also a greater representation of the voices of the women who were interviewed twice, as there was further narrative to explore.

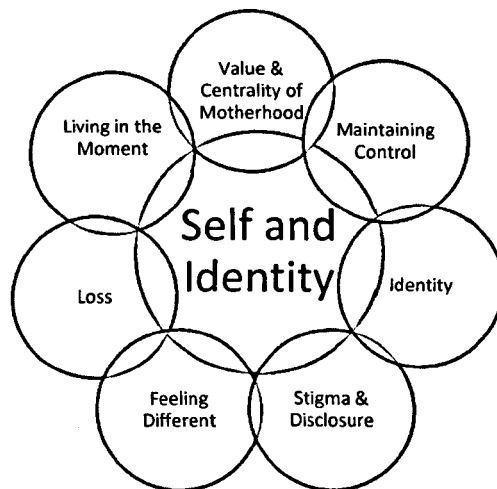
The following chapters will provide the analysis of the women's views from both the first and the second interviews.

Chapter 5 - Self and Identity:

"I'm fine, I mean, I live well...of course, if I didn't have the disease, but...I don't know, for better or for worse it's a part of me!" (Erica).

This quote from Erica expresses how she sees her MS as being part of her identity, and one of the superordinate themes identified was 'Self and identity', which encompassed how the women perceived themselves as women and mothers with MS. Within this overarching theme a number of sub-themes were identified as depicted in the following diagram.

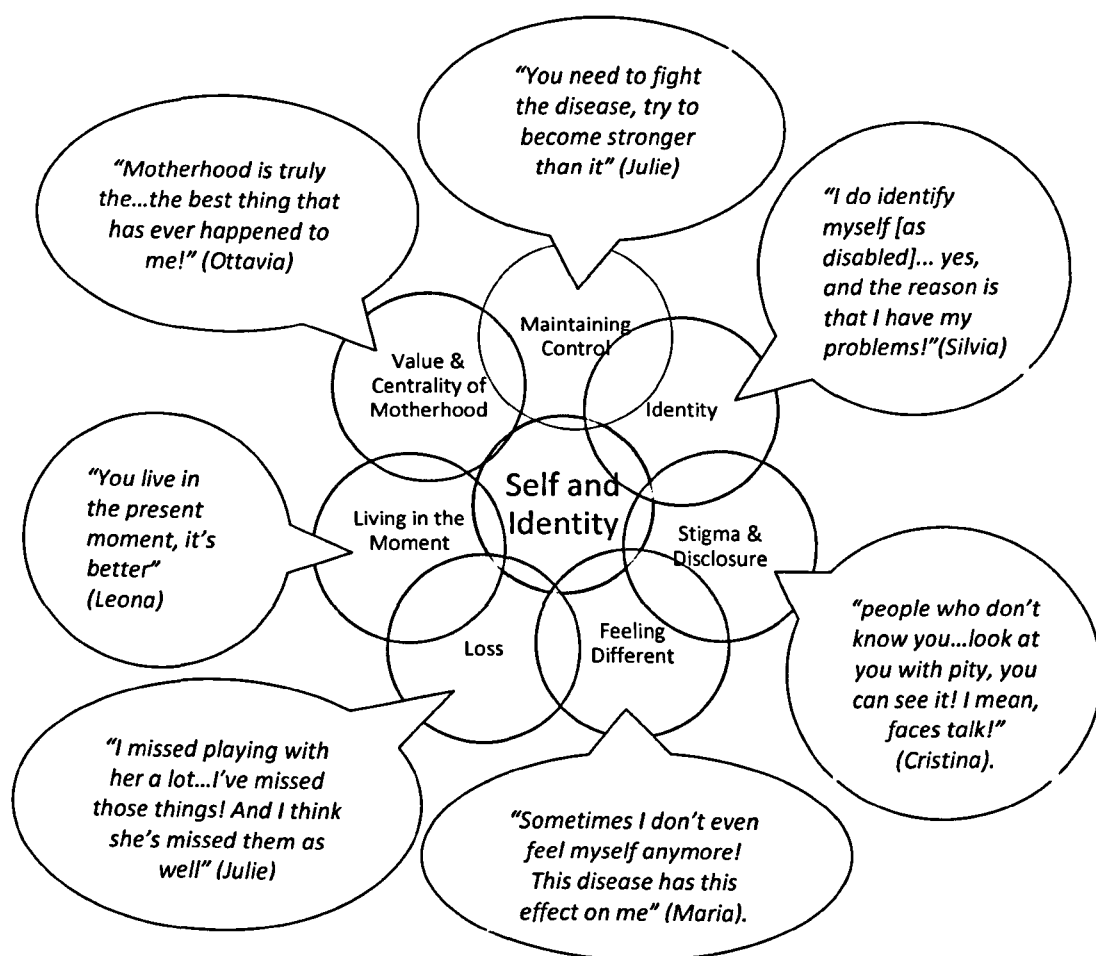
Figure 5.1 Superordinate Theme of 'Self & Identity' & Underlying Sub-themes.



The high value placed on motherhood was evident in the women's accounts, regardless of the level of impairment the women had. Some women reported they felt stigmatised on account of being a disabled woman and linked to this were feelings of fear of stigma for

their families. The issue of control arose in many accounts, including how women strove to battle against the symptoms of their MS taking over their lives. Related to this battle with MS was how some women described feeling different and for some, this led to a sense of loss. How the women defined their identity as disabled, and how they viewed their lives in terms of living in the moment are further sub-themes that emerged. The diagram below shows a representative quote for each of the sub-themes, linked to the superordinate theme of 'Self and Identity'.

Figure 5.2 Representative Quotes to Demonstrate the Sub-themes.



5.3 Value and Centrality of Motherhood.

A key finding from my study was the immense value placed on the role of being a mother, regardless of the stage of the women's MS and whether they were diagnosed before or after having children. When asked a question about how they viewed their life as a mother, all the participants indicated the huge value they gave to this role.

"it's the best thing in the world to have a child! I mean, for me, mmm, I can't imagine my life without children!... [my son is] such a priceless...limitless source of joy!" (Erica).

Even for those who told us about the difficulties in dealing with their adolescent children, the enormous positivity of being a mother was still apparent, for example Fiorella told us her daughter was the joy of her life.

Both Erica and Fiorella were aware of their diagnosis when they chose to have their children, so it could be suggested that they had had the opportunity to actively prepare to be mothers with MS and valued their role as mothers more because they knowingly entered into motherhood with full knowledge of their condition. However, the value of being a mother was also expressed by other women who did not know they had MS when they became pregnant. Julie, who was unaware of her condition, told us that being a mother was *"The most wonderful thing!"* although she deliberated as to whether she would have decided to have a child if she had known she had MS. Although rejoicing in her role as a mother, Julie's contemplation as to her decision-making around becoming a mother indicates that the pre-existing knowledge of a diagnosis of MS is influential (see 7.6 'medical influence and decision-making'). In discussing the importance of the role of mother, a number of women made reference to how they prioritised the role of

motherhood over other roles, and sometimes over the existence of MS itself. Rosa told us that she did not think much about her MS, instead focusing on other goals related to looking after her children. This put to the forefront managing her children's needs, rather than her own.

Prioritising the role of mother over the existence of MS is also discussed within the sub-theme of 'maintaining control'; in terms of how prominently women felt MS featured in their lives. However in demonstrating the enormous value placed on mothering, it is relevant to consider how this role lessened the importance of other life roles and experiences, which became secondary to being a mother. For Sonia, who was a busy working mother she told us:

"all the other things don't count as much and ...I do not want to say, at the end of my life, that I was a good, or capable [professional], I want to say that I was a good mother! That's truly the most important thing to me, even if it doesn't seem that way because I do so many other things, but it is my main priority, no doubt about it!" (Sonia).

Other women prioritised their role of mother above work roles, often giving up work to focus their energy on mothering tasks and doing activities with their children. This was evident when my participants discussed juggling motherhood and work; as Leona told us her view was that a woman could either be a mother or a career woman, as combining the two would be difficult. Although this balance between work and motherhood can be a challenge for all women, the added factor of MS was also influential. Erica was one of only two of the women interviewed who was in paid work and she told us that following a recent relapse, she was starting to struggle with the combined demands of caring for her

children and continuing in work. Her hidden symptom of fatigue was beginning to influence her dual roles of mother and worker, and she was reaching the juncture that others had come to before her, of placing her role of mother above the role of worker, focusing her energy onto that role. However, there may also have been other restricting elements that precluded women from being both mothers and workers, with outside influences limiting the participation in both roles. For example, as well as fatigue being a restraining factor in juggling roles of mother and worker, some other women had finished work because of a lack of accessible facilities (see 7.4 'barriers to activities').

"I also hated going to work in a wheelchair, I mean, then when I had to go to the toilet, I had to have someone accompany me..." (Elisa).

Many women spoke of how they had enjoyed their work and expressed some sadness that they were unable to continue, not least because of the loss of valued 'friendships' (see 6.3 'friendships').

However, in spite of the loss of the work role for many women, the role of motherhood appeared to provide some recompense, and helped reduce feelings of regret at not being able to work. Both Elisa and Alessandra, though expressing sadness at having to give up work, reported feeling content in their mothering role. Alessandra told us motherhood fulfilled her and took priority over her MS. Even though her impairment had been influential in her decision to leave work, Alessandra's MS was secondary to her role as mother, shifting into the background in relation to her mothering role. Rosa told us that although she no longer worked, her decision to finish working was influenced by her need to balance the demands of having children alongside her MS, but also because of her husband's views.

“then my husband said ‘what are you thinking going to work with two children and home and this and that?...what are you thinking?’ I’d truly like to go to work, but he doesn’t want [me to]”(Rosa).

This comment by Rosa’s husband suggests a more traditional view of women being either mothers or career women (see 6.5 ‘shifting of roles’). However, the enormous value placed on the role of motherhood for my participants may also be influenced by this more conventional approach to the centrality of this role. This was reflected by comments made in terms of motherhood as defining femininity.

“a woman is a woman when she has a child” (Julie) and “a life without being a mother doesn’t...doesn’t make sense!” (Fiorella).

What is particularly poignant about these comments and this approach to motherhood linking to femininity is that in this cultural context, if the role of being a mother is not fulfilled for women, there may also be a consequent impact on aspects of how women view themselves. Taking this into account, how women who knew their diagnosis were supported in their choice to become mothers will be relevant to consider, as being women with MS, there will also be medical deliberations and the role of doctors will therefore be pertinent with regard to decision making on motherhood choices (see 7.6 ‘medical influence and decision making’).

The above examples illustrate the sub-theme of the value and centrality of motherhood for the participants in this study. Many had needed to give up work because of their MS, some because they had prioritised their children above their worker role, and others because the lack of accessible facilities had left them with no choice but to surrender this

role. For others, the cultural expectation of prioritising the role of mother over that of worker was also significant, either explicitly or implicitly. The women all expressed the importance of their role as mothers, with their MS often placed in a secondary position, being relegated to lesser importance than the esteemed role of mother. The social and cultural construction of motherhood will be explored further within the discussion chapter. The following sub-theme will expand on this positioning of MS further; considering the presence of MS in the everyday lives of the women and their feelings about how MS manifested itself on a day to day basis.

5.4 Maintaining Control.

Another sub-theme that arose was how the women viewed the power of MS in their lives and how they felt about the control they had over their condition. For example, despite being one of the women who had the least impaired function, Silvia expressed how she felt her MS governed her life:

"I have to do what the disease wants!" (Silvia).

For Silvia, her MS impacted on her role as a mother and had a dominant role in her day to day life. Like Silvia, other women spoke of the power of MS and their perceived inability to fight the disease. The strength of MS and the level of control women expressed in managing it did not appear to be related to the level of the women's impairment, but rather may reflect the resilience the women had developed. Some women spoke of how they sought to retain control over their MS, like a battle between the women's perseverance and the presence and potential progression of MS. Many women spoke of how they found the power to battle against their MS, either through attaining inner strength and determination, or through the strength they gained from others. However,

the analogy of the relationship between the women and their MS as being a battle was not reflected in all accounts and some had seemingly dealt with the conflict. For example Elisa, whose MS was much more advanced, although she indicated her anger at the disease, she also talks about her acceptance of herself as a disabled person.

"I am angry, but I accept myself as disabled anyway...I know that there are things that I can't do, that...yes, that I am sorry not to be able to do..." (Elisa).

So for Elisa, although she was more limited from a functional point of view, she had adjusted to the inner conflict of power and even though saying she was angry, was more accepting in her identity as a woman with MS (see 5.5 'identity'). Other women showed that they were adjusting to having MS in their lives, speaking of how they did what they could, when they felt able to, but acknowledging that they would not be able to do everything they wanted to every day. Sonia demonstrated this when she told us about how she managed the task of ironing and that she kept putting her ironing on top of the ironing board in a cupboard, waiting for the day when she found the strength to do it. Eventually the ironing board collapsed, leaving her looking at a collapsed ironing board with a huge pile of ironing on top of it. Sonia told us that she felt this represented a metaphor for her life, she was waiting to find the strength, but the influence of MS had triumphed on this occasion.

Despite some women speaking of how they battled to gain strength against their MS others, like Silvia quoted above, spoke of how MS was in control.

"I mean, it's hard to understand, you want to do something, but you can't do it, not because anyone prohibits you from doing so, it's the disease that prevents you, and against this disease you are powerless" (Maria).

For many of the women who did not know their diagnosis before becoming pregnant, they expressed anger at having MS and the subsequent loss of control they had over their lives. For example Ottavia spoke about her MS as being in a position of power, alluding to the conflict between her and her MS. She compared her MS to having an 'evil twin' which sometimes allowed her to do things and sometimes did not, with her personification of her MS sometimes winning, showing its strength. The presence of MS in the lives of some of my participants thereby challenged their ability to maintain control of how they participated in daily tasks, causing them to question or compare themselves to their former identity (see 5.7 'feeling different').

Many women, as well as talking about their anger at having MS, also spoke of their determination in moving on and fighting it.

"I like to stay active, especially because if you don't stay active, that's it! You're finished! You don't live anymore! I mean, you're reduced to a pfff!...because if I become used to the disease...that's it! And so, instead, no! You need to react, fight it, try to become stronger than it, than the disease, I fight every day and I always have it with me, I always have it, it accompanies me all the time and I say 'I'll kick your ass!' because, well, you have to fight!" (Julie).

Julie's comment that her MS was with her all the time demonstrates her feeling of the continued presence of the disease in her life and her on-going battle to prevent it dictating to her. In contrast, Leona told us:

"...it's not a serious thing, that's it, you don't think about it...I mean, even if I do think of it...I mean, I think about it and I don't..." (Leona).

For some, particularly those women who had less evident impairment, there was more of a denial of the presence of MS, and Delia told us that she did not speak about her disease to others and pretended it was nothing. However, this inattention to the presence of MS whilst perhaps indicative of the lesser role MS had on the lives of the women, also sometimes led to issues around a lack of understanding from others, (see 6.6 'asking for and receiving help from families' and 7.5 'attitudes to disability').

Finding and having the strength to manage MS was sometimes spoken of as something that was found from within, developing a mentality of positivity. Both Sonia and Silvia spoke of how they retained a positive mind set, though for both women this was by mind over matter. Sonia tried to reject the possibility of her having a relapse and Silvia had initially not accepted that she had MS, thinking she had been misdiagnosed. Because she did not have a major MS attack during her pregnancies, which had been predicted by her doctor, Silvia gained strength from dismissing the existence of her MS.

"I didn't even think I really had the disease and that gave me strength...and if I didn't have the thing where I couldn't walk and had to be in a...in a wheelchair like they told me I'd end up, so I thought 'I don't have multiple sclerosis'...and that, for me, might have been helpful because I went along just fine..." (Silvia).

There was a balance to be found between acknowledging the presence of MS in one's life and having the strength to maintain control over the dominance MS had on a day to day basis. The control the women felt over their MS could also be linked to how prepared they felt in dealing with it and for some, MS was viewed as something that had happened, without any warning or indication, that it had entered their lives without them being

ready for it. This may be because of the age at which MS occurred, in the prime of life (Irvine et al, 2009), when many people were busy fulfilling various life roles and activities.

“because it happened to me a bit too soon, so...right in the period where you’re meant to do more things...” (Delia).

Many women were angry and resentful that they had MS; they felt that they had done nothing to deserve it and that they felt powerless in controlling the disease. The anger and unfairness at having MS was expressed in terms of being a criminal by both Julie and Maria.

“Many people hide away because they are embarrassed to be sick. And this, well, this makes me angry, because, well, if I’d robbed, if I’d have done something wrong, then I should be embarrassed, but a disease, I mean, it’s not like we wanted to be sick...so why in the world would you hide away?” (Julie).

The link between being responsible for one’s disease and thereby incurring feelings of shame and embarrassment reflects the lack of control the women had over their MS.

Other participants spoke of how they gained strength from others, particularly their children and how they strove to remain positive and transmit this positivity to those around them. For Alessandra, this was related to how she portrayed her strength to her daughter.

“but would else should I do? Should I cry? No! I have a daughter who has to live with me and see me with a smile, not crying!” (Alessandra).

For many of the women who spoke of how their positivity was aided by the strength they gained from their children, they were not aware of their diagnosis when they had children. Women spoke of how their role as a mother superseded any shock or apprehensions they had when they were diagnosed, instead focusing on their children. Delia told us that knowing she had a baby to take care of had motivated her to get out of bed each day, which she thought she might not have done had she not had a child to take care of.

Ottavia and Leona also spoke of how they battled with their symptoms and concentrated on doing tasks with their children as a priority. In this way, for these women, the focus shifted from managing the symptoms of their disease, to being concerned with ensuring their children's needs were met. MS was thereby given lesser priority in the women's lives, putting their children first.

"Having to concentrate on them makes me concentrate less on myself, and so I don't...mmm it helps me face things better because they come first and the ... then there's me, then there's the disease" (Ottavia).

Ottavia expressed her view that she had won the battle between herself and her MS, as the MS was in the background, and that prioritising her role as a mother and putting her children first consigned the MS to even lesser importance. Living as a mother with MS, her children held the highest position, then herself, then lastly the disease.

For Silvia, although convincing herself initially that she did not have MS, when her diagnosis became irrefutable, she spoke of the strength her children had given her.

"I don't know where I'd be now, what I would be doing...if I'd have the strength to keep on going and do all the things I do. It is also because of them! Because they need me!" (Silvia).

This suggests that the strength she gained from knowing her children needed her was of equal or even higher importance than the strength Silvia held onto by denying her diagnosis. For the women who made comment about the source of their strength coming from within themselves, more of them knew their diagnosis before having children, suggesting that they had developed some inner resilience to manage the battles between having MS and being mothers, as opposed to those who were diagnosed post childbirth, who were more likely to comment on finding strength from their children. However, although most remarks about gaining strength from children came from women who did not know or doubted their diagnosis when they became pregnant, it was not exclusive to this group. This relates to my research question regarding the relevance of the timing of diagnosis, indicating that the majority of women who were diagnosed post childbirth spoke more about how they found their children to be a source of strength in enabling them to manage their disease symptoms.

"I've always played with my boys, because it gives me the strength to carry o[n]...to do many things! I mean, just taking them in my arms, yes...I mean, sitting them on my lap, it really gives me a lot of strength!" (Erica).

Many of the women, across all three groups, talked of their satisfaction in having raised their children and maintaining their role of mother, whilst also having MS.

"sometimes I allow myself the small pride of saying 'but you have multiple sclerosis, but you did it, becoming a mother and managing your daughter, right'"
(Sonia).

These feelings of self-accomplishment at having successfully raised a child alongside managing the symptoms of their MS, show the pride that women felt at being mothers with MS. As three of the four women quoted above had known their diagnosis, it suggests that pride in having children linked to how the women had shown strength in deciding to have a child, despite unsupportive medical advice (see 7.6 'medical influence and decision making'), and they felt proud that they had made this decision. There is also the element that the women showed their opposition against the perceived power of MS, establishing their authority over the disease in becoming mothers, thereby maintaining control.

Although many of the women who spoke about their pride in being mothers referred to the positive reinforcement they had received from their families and how this made them feel stronger, this was not always the case and will be discussed later (see 6 'relationships with others' and 7.5 'attitudes to disability'). Alessandra told us of a more positive experience and how she felt encouraged by others in having a child, although she felt it was a natural thing for her to have done:

"I've heard it said by many people 'you have incredible courage'! Yes! I think so, I think I did have it! And I'm happy, not because I think myself a heroine!...I mean, for me, it was normal! It was right!...I haven't done anything amazing! The people around me say those things to me...and they make me feel a bit...as they say today 'they don't put me down, they pump me up!'" (Alessandra).

Alessandra expresses the additional strength she has gained from the admiration of other people. What is noteworthy in considering the issue of admiration is that all of the women who knew their diagnosis prior to having children spoke of their own pride or how they felt admired by others. This suggests that their decision to have children with the knowledge of their diagnosis demonstrated them taking control over this aspect of their lives. Only one woman who did not know her diagnosis, Ottavia, explicitly spoke of her sense of accomplishment at having raised her children with MS.

Within the sub-theme 'maintaining control', the issues discussed were around how much control women felt over the presence of MS in their lives, both in accepting and reacting to their diagnosis, but also with living with MS on a day to day basis. Some women spoke about how they gained strength from others, their families, their children and wider society, and other women curtailed the impact of their MS, even to the point of denying its existence. Other women, particularly those who knew their diagnosis prior to having children, spoke of how they found inner strength to deal with their MS. This suggests that the women who knew they had MS felt more confident, or more powerful in entering motherhood with the knowledge of their disease, compared to those who found out about their MS post child birth. The theme of pre-existing knowledge will be discussed later (see 7.6 'medical influence and decision making'), but how open the women were in identifying themselves as disabled people will now be explored, by considering issues around self-identity.

5.5 Identity.

Due to the number of women who talked about hiding their impairment during the first interviews, (see 5.6 'stigma and issues of disclosure'), in the second (follow-up) interviews

we asked women whether they identified themselves as a disabled person. Alessandra told us she did:

“Only because I can’t walk and because I have difficulty getting around and going to pick my daughter up...only because of that. As for the rest, no, absolutely not. I identify myself [as such] only when I find myself facing a barrier, only in those cases, otherwise, no. I feel like a completely normal person” (Alessandra).

Within this statement, Alessandra demonstrated that she viewed her disability as being caused by the barriers she faced, rather than due to her impairment. This was expressed further as she told us that when her life was free from these barriers and she was able to participate in activities with her friends, she became a person who was not disabled. Her identity as a disabled person is therefore constructed by external factors, rather than being attributed to her MS. This may be because Alessandra was impeded in accessing surroundings as she was a wheelchair user; therefore the environmental barriers were more manifest. Another woman who was one of the more impaired women was Elisa, who was not as clear in her articulation of the barriers being influential to her identity as a disabled person, but did allude to this:

“... I do identify myself [as a disabled person], yes...I know that there are things that I can’t do, that I can’t manage to do ...sometimes I try to say 'I'll do it' or I'd like to go to the theatre but thinking about calling to reserve a disabled space is more tedious than anything!” (Elisa).

Although Elisa spoke of things that *she* could not do, her acknowledgment of the need to call ahead to reserve an accessible seat at the theatre indicates that she also recognised the environmental barriers that precluded her full involvement in activities of her choosing.

Elisa and Alessandra were the two women interviewed for a second time who had the greatest level of impairment, and both of them discussed disability in relation to external factors. It is therefore interesting to explore how women who were less impaired described themselves as disabled people. Sonia was reaching the stage where she was considering using a walking stick to aid her mobility. In response to being asked whether she identified as a disabled person she told us:

“Unfortunately I do now... for more or less a year I have considered myself truly disabled, in the true sense of the word, because I am 'not able' to do certain things and so, yes, I feel limited... limited and disabled...” (Sonia).

This description of disability is more in keeping with a medical model definition, where disability is attributed to impairment, rather than to external factors. The other woman interviewed for a second time who was in the group with the least level of impairment (group 1) was Silvia. She told us:

“I do identify myself [as disabled]... yes, and the reason is that I have my problems! I have my problems because before I used to go out to the shops; I would perhaps go to the shops with a friend and now if they say to me 'come on, let's go to [the shopping centre]!' I say no because I have to take the bus and because I have difficulty walking and I get tired, especially now that it's hot out... at the sea, I used to go here, I would go with a friend or with my children when they were smaller and we'd take the train. Now I can't do it anymore and... and so, that is why I find myself saying that I am disabled” (Silvia).

Silvia spoke of how she no longer went to the shopping centre because of her difficulty walking and her current levels of fatigue, and that *her* inability to do tasks was why she defined herself as being disabled. The issues to do with access to public transport, which also impacted on her ability to participate in the activities remained unaddressed. These

environmental barriers were not identified by Silvia as constructing her identity as a disabled person. She expressed '*I can't do it anymore*' rather than recognising the barriers that prevented her participation.

Three women who were in the group with the middle level of impairment were interviewed for a second time; Maria, Patrizia and Ottavia. Their responses to being asked about their identity as a disabled person also alluded to a more medical model of disability, but there were also some indications that attitudes of others and environmental barriers defined disability, particularly for Maria, who used a wheelchair for outdoor mobility.

"Because I go out in a wheelchair and I see that, in some shop... I can't go in because I am in a wheelchair... [and] the shop worker glares at you like you're going to break something... really, sometimes... or you end up fighting with someone or... you just stay outside." (Maria).

However for Patrizia, her definition of a disabled person was directed more towards her impairments:

"Yes because, anyway, I am limited in everything. Before I used to do so many things and now I am limited... in going out, even for a pizza with friends. I avoid that because perhaps I'll get tired and I can't say: will you take me home? So, I'm limited, I'm limited in everything... I don't do anything anymore." (Patrizia).

Ottavia defined herself as a disabled person:

"Because I am not able to do everything a normal person can. I mean, I don't know, if, for example, I go to the mountains with my husband and my daughters and my friends and they all go on a walk, I can't go. As much as I try to do so many

things, I am aware of my limits and I know full well that I can't do everything everyone else can." (Ottavia).

The way in which women defined themselves as being disabled varied, depending on their level of impairment. For the women who were frequent wheelchair users, they identified the environmental barriers which defined them as disabled people. For the women with lesser impairment, their definition of themselves as disabled people related more to their perceived physical limitations, rather than the outside influences on them as people with impairments. There was a shift away from internalising the concept of disability, to attributing the cause of disability to external factors, as the women's impairments progressed. In view of how women identified themselves as disabled people, consideration as to how they disclosed their impairments is also relevant to consider and issues of disclosure arose as another sub-theme.

5.6 Stigma and Disclosure.

In interviewing women at various stages of MS, some outwardly presented as being disabled people, on account of overt physical impairments; and others had impairments which were not necessarily evident to the outside world. A sub-theme that emerged in my analysis was how women concealed some symptoms of MS, or their diagnosis, and the fear or actual stigma associated with being a disabled person. Stigma, both for themselves and for other family members, arose in many women's accounts and women's descriptions of stigmatising attitudes towards them were often linked to pity, which led to some women not disclosing their impairment. Although both Sonia and Ottavia told us they were very open with their children about their condition and

symptoms, both admitted that they hid some aspects of their condition. Ottavia told us, when telling us about an appointment with her neurologist, with regard to her symptoms.

"I am fortunate to be able to live with them...and hide them fairly well" (Ottavia).

This comment suggests that for Ottavia she preferred not to disclose her symptoms to the outside world, which again indicates there was a stigma attached to presenting as a disabled person. This was also evident in the reluctance of women to accept symbols of disability, such as equipment to help with mobility and Sonia told us she was avoiding using walking aids for as long as possible.

Ottavia and Sonia were able to some extent to disguise their symptoms from others, as they had less noticeable evidence of any impairment. In contrast for the women who were regular wheelchair users, their outward presentation to society depicted them as disabled, on account of their wheelchair use. However, there remained a reluctance from some to accept any equipment which would assist them, as it would be akin to dependence, rather than facilitating independence.

"I live in a house with three floors, however, I don't have any intention of putting in a stair lift or something like that because, while I am still able, I intend to make the most of what I have, I mean, I don't want to live like a...that's just what we'd need!" (Cristina).

Although being determined to do as much for herself as possible, couched in this statement is the suggestion that by having equipment in her home, Cristina would be identifying herself as being disabled and that by accepting this, it would cause upset, rather than enhance her life. Cristina was concerned for stigma for her children, as well as

herself. She went on to tell us that, although her daughter saw her mother's wheelchair as perfectly normal and had assisted with pushing her around the supermarket, the reaction of other people was one of pity.

"seeing a nine year old girl pushing you in your wheelchair makes people look at you with pity right? The child's pushing her mother!...these looks of pity...and then, they are wrong, I must say!" (Cristina).

Cristina expressed that her daughter did not feel that she should be pitied, but that the stigma implicit within the pitying looks was clear. For Fiorella, who was a full time wheelchair user, her account shows that the stigmatising attitudes of others impacted on her relationship with her daughter.

"when she was in middle school, she didn't want me to come to meetings with the teachers, like I've always done, I've always gone, because she was ashamed of me! She even said it, 'I don't want you to come because all my classmates will see you, my friends will see that you're in a wheelchair!'" (Fiorella).

Fiorella's daughter had been ostracised by her friends in a previous school, on account of having a mother in a wheelchair, which is an indication of stigma by association, or 'courtesy stigma' (Goffman, 1963). However, in considering the reaction of Fiorella's daughter, there may also be some element related to her age and the typical reluctance of teenage children to be seen with their parents (see 6.4 'relationships with children'). The fear of stigma for their children was expressed by other women, not only those women who were wheelchair users.

"sometimes maybe I'll think to myself 'oh, and what if I run into , my kid's friends...and they see that I walk with a crutch or that...' I mean, I feel bad for them, you know?" (Silvia).

Silvia was concerned for her children, for fear of them being stigmatised as she was a disabled woman, but her apprehensions were not substantiated by her children, who told her not to be embarrassed and worry about other people's reactions.

This difference in how children were felt to perceive their parents, who outwardly presented as being disabled, can be linked to the ages of the children when the mothers became wheelchair users or whether their children had grown up around their parent's increasing impairment. For Alessandra and Elisa, their children had grown up with them as wheelchair users and neither woman showed the fear of stigma for their children:

"he's always seen me [like this], he's not embarrassed of me... I have never been embarrassed! And I think that is how it should be for everyone!" (Elisa).

However, this may also be related to how the women felt about themselves as disabled people. In expressing how she was not embarrassed about being seen in a wheelchair, Elisa derided the stigma and felt that others should too.

This was spoken about by other women, not only those who were wheelchair users. Ottavia did not know her diagnosis when she had her children, but she too expressed that how others reacted was influenced by how one felt about oneself.

"I know that a lot depends on how you present yourself; in the sense that, if something bothers you, it will bother others as well" (Ottavia).

This was reinforced by Maria's account, as although her teenage daughter had dismissed any feelings of embarrassment at going out with her mother in a wheelchair, Maria remained concerned about being seen out in a wheelchair, not only due to fear of stigma for her daughter, but also because of how she felt about it and she told us she was embarrassed to be seen outside in her wheelchair and therefore she sometimes avoided going out.

Maria spoke about how when people looked at her, even if she felt it was intended to be with compassion, it made her feel pitied. This was reflected by other women and could influence decisions to disclose MS.

"I don't divulge the fact that I have MS much. For the precise reason that you can be pi---pitied 'oh, poor thing!'...it's as if you're dying!!!" (Leona).

The freedom with which the women felt able to divulge their diagnosis was to a large part related to fear of pity, but to some extent also correlated with the lack of understanding about their specific condition, or their repressing of the role of MS in their lives, (see 5.4 'maintaining control'). The reluctance to disclose disability was identified by some women with less evident impairment, Silvia being one of these. Silvia had avoided walking with a stick, but then following a relapse, had to walk with a crutch and have disability vehicles take her for therapy in their transport, thereby highlighting to those around her that she was a disabled person. She told us:

"at a certain point, I thought, 'I have to admit it'" and from then on "talking about it was better, perhaps, because I'm better able to face it" (Silvia).

Non-disclosure therefore sometimes became impossible and Silvia was not the only woman who disclosed her MS through necessity rather than choice. Even though Silvia appreciated that things had become easier since she had started to talk to people about her MS, it was not through choice that she disclosed it, and she had told people that she had a problem with her back, rather than openly acknowledge she had MS. However, external factors had put her in a position whereby she was not able to disguise her condition, as when the AISM transport collected her for appointments it therefore became evident to others that she was a woman with MS.

Another example of when disclosure came through necessity rather than choice was from Delia. She told us that she had not discussed her MS with her son until he was about eight or nine years old and this was when she felt she had to:

"he...mmm...obviously because he didn't know or in joking he might push me and perhaps...playing! I might lose my balance and I told him not to push me mmm because I could fall, then he asked me why and so I explained what I had and, anyway, he understood!" (Delia).

However, for some women who either did not disclose their symptoms, for example those who hid their fatigue, this could have an adverse effect. Sonia told us about a period of her life when she was feeling very low and felt that work colleagues were not being considerate towards her and she thought they did not understand her. However, she also recognised that her colleagues could not be attentive towards her MS as she had not told them about it.

"I hide my illness, a bit, I act rather as if I don't have it...Even now that it's been twenty years that I've had it, there are people who say 'what's wrong with your

leg?’ and I say ‘you know, I have multiple sclerosis’ and they say ‘really?’ and there are still many people who don’t know because I’ve never told them because the smaller effects are perhaps less noticeable and so I’ve not spoken about it!”
(Sonia).

The women were caught in a trap of disclosing their disability and feeling pitied, and not disclosing and therefore not having their needs recognised. Cristina told us that her desire to continue to do as much as she could for herself, avoiding asking her family for help sometimes led to her feeling annoyed that her family did not notice when she needed help.

“sometimes I get angry because they are used...they are used to the fact that I always do everything on my own...I’ve never asked anyone for help...now on days when I might not feel well, it’s not like I complain...and you might see but you don’t think about it! I mean, I see that sometimes even my husband, I mean, he’s a wonderful person, my husband, but sometimes even he doesn’t notice!” (Cristina).

This also created an internal discord for Cristina who was trying to maintain her independence but recognised that she needed assistance. This links back to the issue of pride and strength that women showed. The desire to remain strong and continue to retain independence conflicts with the need to call on assistance when it is needed. However, sometimes, not outwardly appearing to be disabled could be seen to create more difficulty, due to the attitudes of other people. Ottavia recalled a situation at a restaurant where another woman had been staring at her family as they ate a meal. As she was physically unable to help, Ottavia had sat at the table whilst her husband went back and forth fetching things and helping the children. The woman had later apologised

to Ottavia as she had thought badly of her and assumed she was being lazy. Whilst sitting at the table Ottavia's MS was not visible to the outside world and therefore the understanding of why she was not helping her family was misinterpreted by onlookers. Ottavia concluded that with regards to not outwardly appearing disabled:

"it's a blessing and a curse, in the sense that sometimes you know you can't do something and sometimes you have the desire to shout it out to the world that 'I can't do it and so I need help'" (Ottavia).

There was a contradiction between incurring pity from others, as opposed to having appropriate assistance. Ottavia compared her lack of visible symptoms to other people, to being a wheelchair user and she expressed that to some extent it would be easier if she used a wheelchair, as this depicts to others that assistance might be needed, as opposed to hidden symptoms of disability, which were overlooked by others. Similarly for Leona, who in talking about the level of responsibility she carried in her life told us:

"Sometimes in my life I wish I had a limitation...I ask myself, in fact, I often say to myself 'what if I were in a wheelchair'" (Leona).

Like Ottavia, Leona is also indicating that if she were a wheelchair user, there might be more understanding from others. These findings demonstrate the perceived lack of understanding felt by those women who were not users of aids and equipment, and the fear of stigma for other women who were reluctant to accept equipment. For Alessandra however, who was a regular wheelchair user, she took a more scathing outlook on those who might view her with pity:

"...what I really never want to hear anyone say is 'oh, poor thing, she's in a wheelchair!' What idiots! Yeah, yeah, I am in a wheelchair, I don't walk! I might not be able to write well either but...bah" (Alessandra).

Alessandra's comment of "bah" is an Italian colloquialism to express uncertainty. In this context, Alessandra is using it to express her lack of conviction that her being in a wheelchair constitutes her being considered a 'poor thing'.

There was also evidence that family members were aware of the stigma of outwardly being seen as a disabled person. Within Ottavia's family they were open about her MS and she had a good group of friends who helped out and enabled her to participate in her children's activities. However, her husband still worried about how people would react to her if they did not know her and they saw her with her walking aid or her wheelchair. Her husband had tried to discourage her from going to an activity which was outside of their usual social circle and when Ottavia was insistent that she should go, with reluctance, her husband said "People will look at you with your walker". This concern for how unfamiliar people would respond to Ottavia when they saw her with a walker or a wheelchair indicates his concern with regard to stigma not only for Ottavia, but also for himself and their children.

For many women then, issues of disclosure and acceptance of equipment and assistance were linked to fear of pity and stigma for themselves and for family members.

Stigmatising attitudes from others were related not only to how society would respond to them as disabled people, but also sometimes to how their children would feel about being seen with them in public, or how some women felt about being seen with walking sticks or wheelchairs themselves. This element of acceptance of equipment is also

discussed under 'relationships with children' which links to how open the women were in discussing their MS with their children. To some extent, for those women who had the greatest level of impairment, there was a demonstration of strength in their accounts about how they rebuffed the looks and attitudes of others. However, fear or realised stigma was implicit in many participants' experiences, no matter what stage of their MS (see 7.5 'attitudes to disability'). This also relates to how some women and their children made comparisons, mainly to themselves pre and post diagnosis of MS.

5.7 Feeling Different.

For many women, the issue of comparison was spoken about during their interviews. This arose in how they felt their children compared them to other mothers, or to how they were as mothers before they had MS. At the same time some women made comparisons between themselves and other mothers, or in how they identified themselves as mothers with MS compared to before they were diagnosed.

Many women (regardless of their level of impairment) felt different and manifested a new identity as a woman with MS. This was the case for Maria and Patrizia, who spoke about their identities before and after having MS. Patrizia related this to tasks she used to do, before her mobility became impaired.

"What I did before was something totally different; it's a second life, this is."

(Patrizia).

Maria told us:

"my oldest has seen me normal and then has seen me the way I am now. The youngest, instead, only knows me as I am now..." (Maria).

Maria compared her "normal" self to her current self and how her older child had seen her as a mother both before and after she had been diagnosed with MS. She differentiated between her younger child who had only known her current self, and so was not able to compare the pre and post MS mother, and her older child who could. The subject of comparison arose in the accounts of many of the women who had more than one child, particularly in terms of tasks formally done which were now not possible or more challenging for the women. The issue of comparison was most discernible for those women who were not aware of their MS before having children, which became apparent after the birth of a successive child. That is, they compared their mothering role between each of their children. Cristina told us that when thinking about her role as a mother with her youngest child:

"because sometimes I don't have...mmm...I haven't felt that I was a mother in the full sense of the term, sort of a 'half' mother! And that's something that makes me feel bad!" (Cristina).

This was also the case for Ottavia who spoke, like Cristina, of not feeling wholly present in her daughters' lives, and her realisation that she could not be there for her children all the time which was difficult for her to reconcile with herself.

Both Ottavia and Cristina compared things they had done with their older children, which were more difficult to do with their younger child. Ottavia also considered whether her children might perceive the differences. She spoke about how her daughters compared her role as a mother by looking at photos and through discussing activities that they had

previously done together. Her eldest daughter remembered times when her mother used to be able to do lots of physical activities with her, which were no longer possible due to Ottavia's mobility difficulties. Her younger daughter had never known her mother any other way; she had grown up with her mother's MS and perhaps had adjusted better to Ottavia's limitations. Ottavia worried about how her older daughter noticed the differences in what Ottavia could do before, and how she would continue to recognise these differences as she grew older.

Cristina told us that she felt guilty about her perceived different roles between her children.

"I do feel a sense of guilt. The other two had a mother that was always on form, and since she was little she's had a mother with problems..." (Cristina).

Cristina told us that when she was able to take her youngest child to activities that she took her older children to, that she felt happy and because she was replicating the things she did with her older children, she felt more of a mother.

Ottavia's younger daughter commented on how her mother did different activities with the older child than she did with her. However, Ottavia's comments about how her daughter compared 'the before and the after' relate to how she noticed changes and compared herself:

"I am the one who can't ski, the one who can't go with them, who can't drive, so it's normal that they compare me to the other mothers" (Ottavia).

As indicated in the above examples, Cristina, tended to be the one comparing her role as a mother, rather than her children doing this. For the other women with the greatest

level of impairment, who perhaps were more likely to identify discernible differences between their pre and post MS selves on account of them being more impaired, three of them commented on how their children compared or questioned tasks they could do. Fiorella and Francesca both had teenage daughters who had openly questioned them on whether they would participate more in activities with them if they did not have MS.

Francesca's daughter, on finding out her mothers' diagnosis had asked her:

"but now that you're sick won't you do anything?" (Francesca).

Alessandra's daughter was still very young when we met and had only known her mother to be a wheelchair user, as had Elisa's son. Their children therefore would not have remembered their mothers any other way than as wheelchair users, although Elisa's son did reflect on when she had been more physically active.

"...he asks me 'do you remember when you were better? And we were playing with my playmobil?" (Elisa).

For the women who had a more advanced level of MS, issues of comparison were raised more by those with older children who could remember their mothers prior the progression of their MS, than those whose children were younger when they became impaired. As well as the women with more than one child making comparisons between their mothering role with their children, some women also compared their role of mother with other women. Julie spoke of how she felt different from other mothers because the lack of disabled facilities meant that she had to struggle to access things and then was exhausted. As there was no lift at her daughter's school, she had to climb the stairs to reach the classroom.

"You arrive really tired, having climbed all those stairs...you arrive so tired...I see all the other mothers smiling, happy...laughing and talking...and I can't! I feel...different" (Julie).

When Julie compares herself to other mothers it is the environmental barriers which impede her from fully participating. (see 7.4 'barriers to activities'). For many women, because they compared their roles with other mothers, they went to great lengths to make sure their children did not miss out on participating in activities, in order to ensure that they met their perception of the required standards.

"I've always, I've done everything that the other mothers have, I haven't done anything less! Even if I've forced myself, perhaps arriving home exhausted, but I've always taken him all over...I've always helped him to do whatever he needed to, I've never made him miss out on anything..." (Delia).

Elisa also spoke about ensuring her son did not miss out on activities, but her approach was to fill his days, perhaps to prevent him from making comparisons.

"perhaps his day is so full that, that he doesn't manage to...to think about what he's missed?" (Elisa).

Elisa endeavoured to ensure her son's life was not compromised by her impairment, by ensuring he did not miss out on activities that his peers did. Other participants also spoke of how they strove to ensure their children did not miss out and had adapted tasks or delegated them to others, (see 6.5 'shifting of roles'). However this renegotiation of tasks through adaptation or delegation led to a feeling of loss of role for many women.

5.8 Loss.

Some women spoke about how they felt a sense of loss, having feelings of regret, both because their children saw them managing the symptoms of their disease, but also through the realisation that they had missed out on activities with their children. Because of this, many women went to great lengths to ensure their children participated in activities, even when they were unable to see and enjoy these activities with their children. Patrizia spoke of how her son saw her suffer, but her words also show a sense of loss related to her not being able to do activities with her children.

“he sees me suffer, he’s always seen me suffer, but before perhaps I was a bit more...dynamic, and now, instead, I’ve slowed down a lot, even...I’ve always wanted to be with them more, to mmm, I don’t know, to have fun with them, to go out with them, but, unfortunately...I can’t do it” (Patrizia).

Many women strove to ensure that this sense of loss was minimised for their children, making sure that they did not miss out on activities, even though this could come at a personal cost. For example Maria told us about how she felt on a family trip to Euro Disney:

“Do you know what it was like for me to be there in the wheelchair and watch my husband go on all the rides with the children? And me just sitting there...you have no idea what it felt like! But I had to do it!” (Maria).

On this family trip Maria felt loss at not being able to participate in these activities with her children, though her husband was able to fulfil this role, and her comment ‘I had to do it’ shows that she felt obliged in her role as mother to let her children have this

experience, even though she knew she would be not able to participate in the way she wanted to.

Other women also similarly spoke about missing out on everyday activities and although this was the case both for women who knew and did not know their diagnosis prior to having children, it was only evident in reports of the women who were more impaired, probably because of the environmental barriers which prevented them from participating in tasks (see 7.4 'barriers to activities'). This is clear from Fiorella's sense of loss at activities she could not do with her daughter; although the ability to ride a motorcycle was most likely related to her physical impairment directly, the other activities related to issues of access.

"I would have liked to have been a mother who took her out on my motorcycle! I would have liked to have been a mother who went to the beach with her, to the pool with her; I would have liked to have gone on holidays with her, just us two..."
(Fiorella).

As well as talking about their feelings of loss at not being able to participate in activities with their children, women also considered that their children would feel that they had missed out.

"I missed playing with her a lot, not physically playing with her, going to the park, running together, kicking a ball around, si...those are silly things! Chasing each other...I've missed those things! And I think she's missed them as well" (Julie).

For some, there was a sense of loss for their children when women had been able to do tasks previously, which were no longer possible and Patrizia told us she felt her daughter suffered as she was no longer able to do activities with her that she formerly had.

As well as thinking of activities they and their children had missed out on, some women also commented on their frustration at straightforward tasks, previously done without a thought.

"...normality doesn't exist anymore, the stupid, normal things, that everyone does automatically, for me, just as for everyone else who is sick, are no longer automatic! They all have to be thought over, rationalised..." (Julie).

This needing to plan and consider everyday activities caused women to reflect on how their symptoms impacted on their everyday lives. Fiorella, Elisa and Julie all commented on the preparation needed before doing activities, which led to a loss of spontaneity.

Activities that would be assumed to be everyday to most mothers, sometimes proved to be problematic in a wider sense. Alessandra was not able to go into her daughter's nursery school due to the steps, which had a knock on effect to her mothering role. The inability to access her daughter's nursery led to a further sense of loss for Alessandra, who realised she did not know her daughter's day to day life in school.

"I don't even know where they keep the...mmm... I don't know, the slippers when they arrive at the nursery school! I don't know anything! And it makes me feel really bad!" (Alessandra).

Within the sub-theme of loss, the women spoke of how they realised they could no longer do tasks, either that they had done with older children, before their MS led to their

impairment, or because they looked back and recognised that tasks previously done without a thought, were no longer possible. This led to a direct sense of loss for the women, feeling they had missed out on activities with their children, but also to concern as to how their children might perceive a sense of loss. Many women had therefore striven to fully engage their children in activities, despite knowing they would not be able to participate themselves, to prevent their children realising any loss. Often tasks were delegated, (see 6.5 'shifting of roles'), but delegating tasks to others did not necessarily remove the feeling of loss from the women. The women who spoke about their own loss and concern for their children feeling a sense of loss were women who were more impaired (groups 2 and 3). It is therefore likely that losses were caused by other barriers, such as environmental and attitudinal barriers (see chapter 7 - 'Challenges and Support within Society'). However, it also suggests that women in these groups took time to look back and reflect on their roles as mothers, considering their past as well as their present situation. Whether women lived in the past, present or looked to the future arose as another sub-theme.

5.9 Living in the Moment.

During the course of the interviews, it became apparent that some women spoke very much about the here and now, whereas others looked back and told us about their past lives. It could be assumed that thinking about the past would be more likely for the women who were more impaired, who perhaps looked back on their past abilities, which would accord with the issues raised in the sub-themes 'feeling different' and 'loss'. We therefore began to ask women whether they felt they lived in the past or present and how they felt about their futures. In speaking about their experiences of being mothers

with MS, many women told us that they lived in the present moment, although some lamented on the past and others thought about what the future would hold and were aware of its uncertainty. As the prognosis of MS is variable, some women were mindful of the ambiguity of their lives.

"everything is an unknown with this disease here!" (Elisa).

This feeling of uncertainty was not limited to the experiences of the women with more progressed MS, and led to some considering how much control they had on their future. For example Maria told us that she no longer felt she was master of her own fate. This links with issues of control discussed under the sub-theme 'maintaining control', and perhaps because of the uncertainty of their prognosis and the potential strength of MS, many women spoke about how they lived in the moment, appreciating the present.

"Live for the day...live for today and don't think about tomorrow!" (Leona).

Other women also spoke of how they tended to live in the present, but sometimes also conjectured on what the future may hold.

"I'm much more focused on living in the moment than thinking about the future... I don't see the future as a thing... in the sense that, having a wonderful present, living in a wonderful present anyway both are... I think that the future will also be... perhaps different, but not worse! Only different!" (Ottavia).

Ottavia maintained an open mind about what the future would hold, considering it would change, but not necessarily for the worse. Fiorella was less positive about the future and, mindful of the uncertainty of MS, she was more wary about what was to come, which influenced her tendency to live in the present moment.

"I can't imagine the future and I don't like to think about it, I'm afraid. And so I live for the day, because I know that MS is like the sword of Damocles that you have...you have hanging over your head, you might stay like this and be fine for your whole life or you might find that tomorrow you are suddenly immobile...so I live for the day!" (Fiorella).

When the women spoke about living in the present, most related this to how they felt about their disease progression. However, Delia, Leona and Ottavia also thought about the future in terms of their families, with Delia thinking about how she would fulfil a future role of grandmother and for Leona about how her son may need to assist her in the future. Ottavia took a more general view, but considered life was more straightforward for her and her family if they took each day as it came.

"the unpredictability, the question of knowing, today I will do this because I am not sure I will be able to tomorrow. Perhaps tomorrow I will not be able to do it again; perhaps tomorrow I will do other things that I could not do yesterday...so it's easier for everyone to live day by day – both for me and for everyone close to me..." (Ottavia).

Laura also thought about the future in relation to her family and, like Fiorella, she was less positive about what her future would hold and was one of the few women who explicitly expressed concern about her future in relation to her role as a mother. Although Leona pondered about whether she would become a burden to her son when he was an adult and may need to assist her, Laura expressed her worries about not being able to fulfil her son's needs.

"you are afraid of getting worse day after day...to be able to...to be able to...I'll tell you sincerely that the biggest fear that I have is ending up in a wheelchair. In that case I don't know how much help I'd be to my son...in the sense that, up until now, for better or for worse, with a lot of difficulty, I'm a mother in all respects".

(Laura).

Laura's concern was in relation to her disease progressing and her needing to use a wheelchair, which was a fear also expressed by Delia.

Although some women spoke of how they thought about the past, but tried not to think about lost abilities, Patrizia was the one woman who when remembering her past and the times when she was less affected by her MS symptoms, became very distressed and continued to ruminate on the past.

"[I live in] the past because, anyway, I think about it when I was well! Eh! How could I not think about it? Eh! Unfortunately!...Because...I am...mmm I always said I'd give [starts to cry and then continues more quietly] damn it all...You don't even know...[sobs then continues]...mmm I'd give...I'd give ten years of my life just to be well [begins to cry again, sobbing]...ten years of my life to have one month as I once was!" (Patrizia).

Similarly for Fiorella, although she told us she did not consciously think about the past, she did dream about the time when she was still able to walk. However, she tried to live in the present moment, as she knew that thinking about the past would upset her.

Ottavia, Cristina and Rosa all told us that they tried not to lament on the past and regret not being able to do certain things anymore, but instead tried to appreciate what they

had and to focus on the present. Rosa took a more blasé approach to this, dismissing her thoughts about difficult times in the past and instead living in the present. She told us she lived:

"Not the past, especially because I forget about when I've been unwell, about when...mmm, no, I forget about those things! I think about today, when I'm well! And tomorrow....tomorrow, we'll see! And as for yesterday when I wasn't well, who cares? It has passed! I've gotten through it!" (Rosa).

As can be seen from the above examples, there was a tendency for most participants to live in the present moment, due to the unpredictability of MS and the uncertainty as to what the future may hold. That said, some women considered their futures and were indifferent to it, and others thought about the future in relation to their disease progression, with some thinking about the impact on their families. Some women also thought about the past, with Patrizia becoming distressed when discussing this, but other women dismissed thoughts about the past as they knew they would be too upsetting to deliberate, or they were keen to focus on the present.

5.10 Conclusions on the Superordinate Theme of 'Self and Identity'.

In expressing her identity as a woman with MS, Erica told us:

"I have multiple sclerosis...I don't...I mean, I don't know...I don't know even with what words to say it...a person with multiple sclerosis, very probably, yes...has motor control problems...but their brain, their heart...are like those of other people...so...perhaps I fall a bit, perhaps I lose my balance, but it's not...mmm it's

not what holds me back...nothing holds me back! With my relationship with my children as well, that doesn't...nothing holds me back! Because, in my opinion, love surpasses mmm...surpasses MS...and any other disease in the world" (Erica).

The above quote from Erica highlights her perception as a mother with MS and how she identified herself within this definition. Whilst acknowledging her MS and the functional impact this had on her, it is evident that her love for her children took priority in her life and her MS was put into the background. This was the case for many women and the 'value and centrality of motherhood' was evident in the accounts of all the women. Erica's comment highlights the positive thinking that many women spoke of and how women strove to 'maintain control' of their MS, with some women viewing their MS as being of secondary importance, being a part of their make-up, rather than being dominant in their lives. For other women their self-perception as mothers showed that their MS was more intrusive:

"Being a mother with multiple sclerosis, mmm I am ... I feel absent! Many times I've felt absent in caring for my children, with...with the house! Yes, I....the disease has really....really beaten me down!" (Patrizia).

The concept of being 'beaten down' that Patrizia described accords with the accounts of other women, who spoke of their on-going battle with MS, being ever present in their day to day existence and led to some making comparisons in their lives and 'feeling different'. Some women spoke of their determination and how they adopted a positive and optimistic attitude and some expressed their pride in being mothers with MS and how they had shown strength and felt achievement in becoming mothers, enabling them to remain in control of this aspect of their lives. However other women spoke of their feelings of 'loss' at how symptoms of their MS had precluded them from fully

participating in their children's lives. The women who spoke of loss and who made comparisons were mainly women who were more impaired and these women tended to look back on the past more. Some women also thought about their futures, but some with trepidation as to what the futures would hold for them and their families. The majority of women though tended to express themselves as 'living in the moment', appreciating the present and living each day as it came. As well as the impact of the symptoms of MS, another prohibiting factor in the women's lives was fear of 'stigma', both realised in the form of pity from others, and the perceived and actual associated stigma for their families. This contributed to why, for some women whose MS was not outwardly evident, they were reluctant to 'disclose' their condition, with some women either purposefully or less intentionally concealing symptoms of their MS.

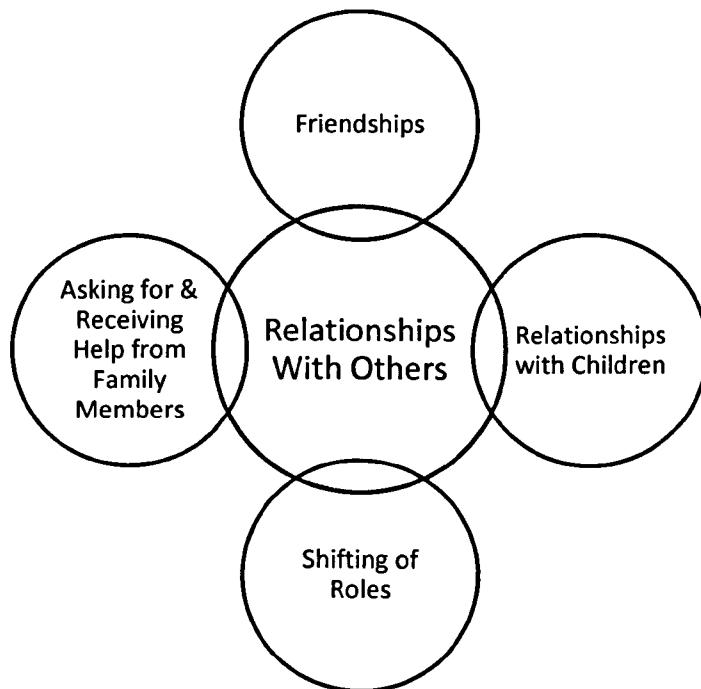
This chapter considered the overarching superordinate theme of 'Self and Identity' and the sub-themes within. It has explored how the women identified themselves in relation to their role as a mother. The following chapter will consider the superordinate theme 'Relationships with Others' and how the women reported their relationships had been influenced by their MS.

Chapter 6 - Relationships with Others:

"I had my husband at home...he stayed at home and he helped me, my parents helped me, I have always had the support of someone, out of necessity!...no always, they've always helped me, with anything I needed..." (Patrizia).

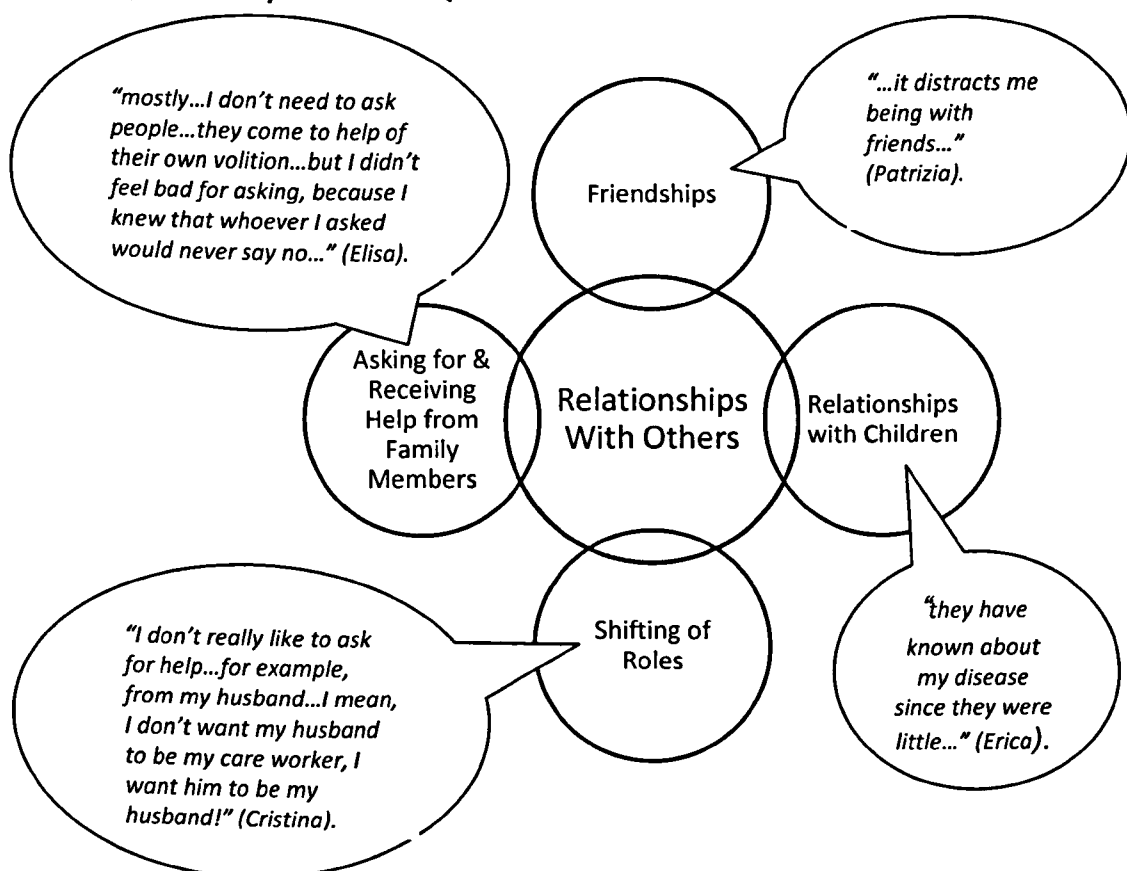
The above quote from Patrizia typifies the situation of many of my participants, in terms of their reliance on interfamilial relationships. The second superordinate theme identified was that of 'Relationships with Others' and how these were influenced by the women's MS.

Figure 6.1 Superordinate Theme of 'Relationships with Others' & Underlying Sub-themes.



Friendships were mentioned by a number of the women, in relation to support gained from friends, but also how some friendships had been lost. Many of the participants talked about their relationships with their children and whether their MS influenced these and they spoke about how they had discussed their MS with their children. Some women expressed how they admired the independence and compassion of their children, particularly younger children, which contrasted with others speaking of difficulties communicating with and managing adolescents. As shown in the above diagram, relationships with husbands, regarding how roles changed was also discussed by some of the women. Finally, the role of other family members was raised, in the context of the provision of both physical and moral support, and sometimes a lack of understanding of how much support to offer or about MS in general. Firstly, the theme of 'Friendships' will be considered. The diagram below shows a representative quote for each of the sub-themes, linked to the superordinate theme of 'Relationships with Others'.

Figure 6.2 Representative Quotes to Demonstrate the Sub-themes.



6.3 Friendships.

Loss of friendships was discussed by a number of the women; sometimes this was because they were isolated in their home environments as access issues meant that they were unable to get out (see 7.4 'barriers to activities'). Other women had had to give up work and therefore lose the companionship and connections with work colleagues.

Patrizia was one of the women who, in thinking about her relationships with friends, spoke of her relationships with former work colleagues.

"...and I always got along with my colleagues, we would also go out together and...that's it, I was always...and so everyone got along, we'd go out together every so often...[long pause]" (Patrizia).

Patrizia's pause at the end of this comment suggests she was lamenting the loss of friendships and this was similar to many of the women in my study who commented on the value of friendships in their lives. For Alessandra, who was more physically impaired, she also remarked on the value of friends who assisted with practical childcare tasks:

"I have a friend who is really there for me...when...she often comes to our place to eat and she does the washing up, and she gets [my daughter] ready for her nap, she puts her to bed, I mean, she helps me a lot! She helps me so that we can go out as well!" (Alessandra).

Whilst Alessandra appreciated her friend's assistance with the practical child care tasks, the value placed on the activity of going out was also evident, showing that friends could offer both practical help and friendship. This was also the case for Francesca, another of the women with more advanced MS, who spoke about how her friends assisted her with

practical tasks, but also offered companionship and took her out as otherwise she told us she would be in the house all day.

Both Ottavia and Patrizia spoke about how they had lost former friendships, as friends had detached themselves from them, due to their MS.

"I've lost people who...who I thought were my close friends, who I believed to be very close to me! And instead, they've distanced themselves from me!" (Ottavia).

This drifting away of friendships or the separation of friendships from support may be related to fear of stigma by association. That is, friendships are stigmatised on account of the women being disabled, viewing disability as a personal affliction, rather than an issue to do with external barriers. Loss of friendships may also be because of the limitations faced by women with MS on accessing environments. The women who spoke about loss of friendships were women who had a higher level of physical impairment, who were more likely to outwardly present as being disabled, or who would have difficulty accessing their social environment. In fact many women spoke of how they were unable to get to and from their children's schools and activities, (see 7.4 'barriers to activities'), which would lead to them losing the usual social contacts and incidental meetings that occur between mothers on a day to day basis. Informal get-togethers with other mothers are a common source of friendships that women gain from meeting outside the school gates or whilst dropping off and collecting their children from activities. This was denied to many of these women, particularly those who were wheelchair users, due to access problems with the environment.

This loss was evident in how a couple of the women became distressed when speaking about former friendships and the hurt caused by knowing such friendships had gone.

Patrizia told us:

"my friends have abandoned me..." (Patrizia).

Her use of the word abandoned suggests that she feels her friends left her when she needed them, which may be because as she told us, she enjoyed being with friends and they distracted her from thinking about her symptoms and gave her a different focus.

Laura also spoke of how her friends provided a distraction from her MS, enabling her to socialise and gain support. For Patrizia:

"...it distracts me being with friends because I don't get to often...and I'm happy when it happens, sometimes it happens that perhaps I have a bit of pain when I'm with other people, anyway...I mean, I laugh, I joke and I distract myself, and it [the pain] passes!" (Patrizia).

This loss of friendships is also related to how some women perceived that people who did not have MS could no longer understand them and the lives they were living as women with MS. For example Maria commented on how she needed to talk, but struggled to communicate with other women about her life. She told us she needed:

"..to talk! To talk, to talk...to talk! [but]'normal people' respond to you as they respond to you for... because sometimes I don't feel I am understood...so...I mean, we're spending time together, and when I see everyone busying about and I'm left sitting...listen, you don't know how I feel! [restrains her tears]...because I've always been the sort to...I've always been the sort to get up, do stuff, say stuff, now...now

I can't do anything!...it drives me crazy, you know! It drives me crazy...I at least, I sometimes, I...I can't stand myself!...I can't stand myself!" (Maria).

The quote by Maria indicates that she feels that her friends are not able to understand how she is feeling and demonstrates her frustration at how her relationships have changed, as she is no longer able to participate in social occasions as she once was. Her comment that she had always been the sort to 'say stuff' suggests that she no longer feels able to relate to her friends and talk to them as she did before. Other women spoke of how only other people with MS could understand, and that people who were not living with MS could not appreciate how their lives were.

"you either live with it or you can't even imagine it" (Ottavia).

This issue of how others looking in from the outside could not understand was reflected by others:

"when [people] say 'but I know, I see how you live' they can't know, they can't know, because only I, I mean...only I and people don't understand...but don't...just as I couldn't have understood before, and I realise that, I couldn't understand what it was like to be like this..." (Maria).

Ottavia, Julie and Patrizia, specifically made comments that support gained from the MS centre, AISM, was valued not only for the therapy input, but also for the moral support gained from others in similar situations, a key source of support perhaps in view of their lost friendships. They commented on how they had found companionships through AISM and they felt better understood there. For Silvia, one of the women who was least impaired, she was more reluctant to go to AISM as she did not want to meet people there

who had a more advanced stage of MS than she had. This links with the view of many of the women that it was preferable to live in the present moment and not dwell on or think about what the future may hold, which also reflects the uncertainty due to the unpredictability of MS (see 5.9 'living in the moment'). Maria spoke about how other women who were disabled would be able to understand her life better, as they would be able to appreciate the effort she made to do tasks, which others may not be able to comprehend. This also links to how some women spoke of their families not understanding the effort it took for them to do tasks, which caused frustration (see 6.6 'asking for and receiving help from family'). Elisa spoke about a collective understanding between women with MS, which Maria likened to having a shared means of communication.

When speaking about friendships many of my participants showed how they valued friends for both practical and emotional support. However for some, friendships were lost because of a lack of understanding (see 7.5 'attitudes to disability'). As well as friendships, women also spoke about their relationships with their children.

6.4 Relationships with Children.

When discussing relationships with their children, many of the women spoke about how they had talked with their children about MS and how they saw it as important to be upfront and open with their children. For Ottavia, this was not only to increase her children's awareness of what her condition was, but also for the sake of their relationship with her:

“...they know perfectly what it is and what it entails and what I can and cannot do because if not, it’d be awful! Every time I didn’t manage to do something it would be held against me” (Ottavia).

Ottavia had striven to be transparent with her children about her MS and how her symptoms impacted on her day to day life. She had become aware of her diagnosis when her youngest child was a very young baby and her older child was four years old. For other women, who were already aware they had MS when they decided to have children, being open with their children from a young age was more likely, and by telling children and being candid with them it was seen to demystify MS and decrease the possibility of it being problematised within the family. Erica, Laura and Alessandra had all spoken with their children about MS since they were very young. All commented that through being open with their children, they felt that it made their condition less of an issue; it was just a part of everyday family life for their children.

By telling their children about their MS and how their symptoms affected them, the women facilitated their children’s acceptance of MS in their lives.

“we’ve never hidden anything from our daughter, we’ve always let her be an active participant when it comes to my health problems...In my opinion, it’s right to do it this way, I don’t know...I hope that she doesn’t, doesn’t live with it like it’s a problem” (Alessandra).

In this way, the existence of MS was “normalised” within the family, although this did not totally preclude women’s fear of stigma, either for themselves or their children. However, in attempting to ‘normalise’ MS, women marginalised stigma and their children were more likely to see MS as just being part of who mum was, rather than being seen as a

problem. Like Ottavia, Julie's MS became apparent when her daughter was very young, around a year old. Julie had also included her daughter in conversations about her MS since she was very young and felt that this meant that rather than considering her to be a sick mum, her daughter knew her as she was.

"...I've always been ill and she's always seen me sick...but it's not like she says "Ah, my mum is sick!" absolutely not! I mean, she considers me normal! As a person she considers me normal, I only have...she only sees that I have something wrong with my legs..." (Julie).

This demystification was also relevant to the use of equipment. Ottavia and Cristina both mentioned that by not making an issue out of using a wheelchair, their children had naturally accepted the equipment and for Ottavia she saw that this also had a positive effect on her children's friends. Through being open with their children and disparaging any fears around equipment use, Ottavia and Cristina were trying to lessen the potential stigma for their children, thereby aiming to avoid their children being or feeling stigmatised on account of their mother's impairment. However, both of these women also indicated that they hid some aspects of their impairment, suggesting that whilst they tried to prevent their children feeling stigmatised, they were both still struggling to avoid feeling stigmatised themselves, on account of needing equipment to help them. Women thereby tried to avert associated stigma for their children, despite being unable to eradicate stigma from their lives completely.

There were some distinctions in how children reacted to their mother's impairment, depending on the age of the child when their mother became manifestly disabled. The above examples represent mothers who were either aware of their diagnosis when they

had their children and had discussed this from the start, or those who had relapsed when their children were young and so their children had not known them any other way. An interesting example to consider is that of Cristina and her children's different reactions to her impairment depending on their age. When Cristina was diagnosed, she had two teenage children and one daughter who was nearly six years old. It had taken ten years for Cristina to be diagnosed with MS, though she had many physical symptoms since the birth of her third child. She told us that when she was diagnosed:

"my older children they didn't care about it at all!" (Cristina).

Cristina attributed this to teenager withdrawal, although she told us that she had problems with them when she first came home from hospital after her diagnosis, which suggests that some of their behaviour was related to her diagnosis. However, what is particularly interesting when exploring the reactions of Cristina's children is that she told us that her younger daughter was more receptive to discussing her mother's MS with her, which Cristina suggested was perhaps because she had known about her MS and lived with it since she was young, as opposed to her older two children who could remember their mother before she had MS. Cristina's younger daughter, similarly to Ottavia's younger daughter, had always known her mother as having an impairment, even though neither Cristina or Ottavia had known their diagnosis when they had had their children, the fact that they had always been "disabled" to their children seems to have aided the openness with which issues were discussed and reassured the children. In contrast, both Cristina and Elisa spoke of how communicating with their older children was difficult:

"...and I think that teenage problems between mothers and their children are a fact of life and they will always be there, for everyone's lives and for every type of women, sick or not, and, what's more, you can't cover it up by thinking that it must be because of my having MS..." (Elisa).

Elisa's comment that it was a teenage issue rather than related to her diagnosis would fit with the fact that her son had lived with her MS since he was a young child too, and had always been open about her MS with her son. However Patrizia had been less open when speaking about her MS with her children and told us she was conscious of her children's needs as teenagers, and was reluctant to discuss her MS with them for fear of overloading them:

"I don't burden them with my problems; I talk with them about the problems that they have due to their age...I don't burden them with my bigger problems...no. At home, you know, I often try to hide how I feel. Whether I feel good or bad, I try not to bother them with it, they...I avoid it with them, if I can. Then there are those days when I'm really...that you only have to say [a word] to me and I cry. So, if I can, I avoid [the topic of] my problems; I don't want to burden them with that. That's really all we'd need!" (Patrizia).

By downplaying how her MS affected her with her children, Patrizia was showing her internalised stigma at being a disabled person, and her fear of courtesy stigma for her children. That is, that her children would be stigmatised on account of her being a disabled woman. (The issue of internalising stigma is explored further within the discussion chapter). However Patrizia also told us that she found it difficult to know what to say to her children and how to pitch her discussions with her children at an appropriate level. Other women had utilised resources from AISM to aid them in explaining their MS to their children, with both Cristina and Rosa using books specifically designed for this purpose. Ottavia and Rosa also spoke about how they used humour to deal with issues around MS.

Perhaps then the issue of communication with children is related to how comfortable the women felt about discussing their MS and how they felt about themselves as disabled people. For the women who feared stigma, there was more likelihood that they had difficulty communicating with their children. For those who did not internalise stigma, or who strove to avoid their children feeling stigmatised by being open and discussing their MS, there was more transparency in communication between the mother and their child.

In discussing their relationships with their children many women also spoke of how independent their children were and how they assisted them with tasks. This was particularly so for women whose children had been very young when they were diagnosed, or those who had known their diagnosis before having children, and been open about their MS from the start. Some women said that they had encouraged independence in their children to teach them self-respect and responsibility, rather than because of their own needs:

"...she needs to learn...and no, it doesn't bother me [to ask her to help] I even ask the little one to help, at eight years old, with the broom and dustpan, I say 'clean it!' and he has to clean! It's not because I can't do it for myself or that I'm not well, no, because you both have to learn! I think it's a normal thing..." (Rosa).

However, other women had encouraged their children's independence due to their own needs. Ottavia, Leona and Laura all told us they had striven to encourage independence in their children to make life easier.

"my son's very independent, I've raised him that way, because...out of necessity!" (Laura).

So for some women, there was a compromise to be made between caring and nurturing their children, whilst also encouraging them to be more independent. There was a predicament between wanting to be a carer for their children, and acknowledging that care may be needed for them in the future because of their MS. This dilemma is depicted by Ottavia:

“part of me wishes that she would grow quickly, and the other part just wants to enjoy her as she is now!” (Ottavia).

For some women who had known their diagnosis before having children, perhaps because they had inadvertently facilitated a more independent attitude in their children, they spoke not only about how their children were more independent, but also about how their young children spontaneously helped them. Alessandra told us how her daughter, who was two years old when we met, helped her:

“[she] says to me ‘mummy, [h]elp?’ and she gives me a little hand! She takes my hand, or if she sees me standing, she holds my legs, she holds onto my legs to help me walk! When I go to the bathroom, for example, I get to the door of the bathroom, I put the brakes on my wheelchair, I get up and she holds onto my legs! Or sometimes it happens that, because it has happened, that I hit the floor, I fall, and she says ‘mummy, mummy! [I] ‘[h]elp!’ eh, it’s incredible” (Alessandra).

This natural assistance offered by her young daughter may have arisen as she had always known Alessandra to be a woman who required assistance to walk; that was just how her mother was. For other women whose children had grown up with their mother’s MS, there was also this natural tendency to get involved and assist, and Sonia, Elisa, Erica and Leona all commented on their children’s aptitude to step in and help them. Sonia, Elisa

and Erica were women who knew their diagnosis before having their children; and Leona, although she was not aware of her correct diagnosis when she became pregnant, was advised that she had MS during her pregnancy when she had a relapse. Again, her child had grown up with her MS and demonstrated his willingness to help his mother, and saw this as the natural way of things.

Sonia, Julie, Erica, Cristina and Ottavia all commented on how they felt pride in recognising their children's understanding and compassion. Erica felt that her children had more respect for her:

"they have known about my disease since they were little, so, probably, they also have more regard for me!" (Erica).

This compassion of the children reflects the acceptance they had towards their mothers; that there was no shame, no fear and no stigma for the children in having a mother who has MS. The openness of the mothers in communicating with their children had moderated any feelings of anxiety and had a consequent effect on how their children reacted to them. Ottavia's comment reinforces that how the women responded to their impairment had a subsequent impact on how their children responded:

"I am aware of the fact that it also depends a lot on me, I mean, if I react to my disability in a certain way, they will do the same!" (Ottavia).

For other women who were diagnosed after they had their children, particularly those whose children had been older when they became more physically impaired, some children had difficulty adjusting to having MS in their lives. Some mothers spoke about their children feeling angry, powerless and resentful of the disease. Maria had not been

diagnosed with MS when she had her daughter, but had a relapse following the birth of her second child, when her daughter was around seven years of age:

“I think she’s angry like I am....how can I explain? She’s powerless...sometimes I think that she doesn’t know what to do... I mean, my younger son is used to it because I was like this when he was born, but my oldest is really angry!” (Maria).

Maria’s comments are interesting as she relates her daughter’s anger to the fact that she was older when she became more impaired, or because she had previously known her mother as being more physically able to engage with her. This relates to Maria’s fear of stigma for her daughter and the comparisons she feels her daughter makes between how her mother was before she had MS. Maria’s feelings are similar to those reported by Fiorella who knew her diagnosis prior to having her daughter and also felt that her daughter had a lot of anger because of the disease:

“what she’s lived though, things that a so-called normal girl, doesn’t go through and doesn’t know about!” (Fiorella).

Although by using the phrase “so called normal girl” Fiorella is acknowledging her doubt of the existence of a “normal girl”, she is also relating her daughter’s life as being different to that of a normal life. She is therefore reinforcing the differences between the life for her and her daughter compared to that for a “normal” family. The stigma attached to being a parent with a disability was therefore apparent once more, despite Fiorella’s attempts to be open and communicative with her daughter. This may also be due to the experience of stigma her daughter had actually faced when she was ostracised by her friends, as described earlier, but perhaps was also because, as a single mother, Fiorella

could not delegate tasks to her husband to undertake with her daughter, and share her role with her husband, as many other women had (see 6.5 'shifting of roles').

Women's fear of stigma for their children was most evident when their children were of adolescent age when the women became more physically impaired. There was also an issue for women who were more physically impaired, in terms of their monitoring their teenager's behaviour. For Fiorella, this was due to environmental barriers which impeded her access to venues her daughter went to, but for Cristina and Maria this was due to more general symptoms of MS and the energy required to manage teenage behaviour.

"Because even arguing exhausts me a lot! And I don't want to do it! ...I think that if I fight, or talk, I will get worse, they will seize up...when I get upset my legs seize up, I don't know what to do...I am...everything seizes up...and I don't want to be unwell, so I leave her to do as she likes." (Maria).

The combination of the fatigue caused through arguing with teenagers alongside the physical barriers which hampered the women's full involvement in the lives of their adolescent children could therefore lead mothers to feel that they were losing an even greater degree of control over mothering their children. For those who were already battling with feeling in control of their MS, this could cause further apprehension. The combined factors of managing symptoms of MS, alongside the barriers women faced, will be explored further in the discussion chapter. Perhaps because she was aware of the possible barriers, Julie was the one woman who expressed her concerns about how she would manage her daughter's needs in the future:

"I hope that I can continue to handle her problems when she's older given that I'm like this, I don't think I could handle much...that scares me, because, whilst she's

little, I can pick her up and put her there and deal with her, but when she's bigger, she'll be able to escape from me!" (Julie).

In contrast, Alessandra envisaged how her involvement in her child's life would increase in the future, as her daughter's needs became less physically demanding.

For those with younger children, who would grow up with their mother's impairment, the expectations of the children were often modified. For example Julie and Sonia commented that they felt their daughters had altered their expectations of them as mothers as they were aware of their limitations. Whilst Sonia admired her daughter for her acceptance and willingness to adapt, other women strove to ensure their children did not miss out on activities and pushed themselves to participate in tasks with their children, with the knowledge that by doing so they would suffer enormous fatigue as a consequence. Laura told us:

"I've always tried to be there for him [her son], even if I was unwell. Many times I would have preferred to stay in bed and rest but I 'sacrificed' myself for him, but then it's never really a sacrifice to be with my son, but...I've always tried to stay positive, to not get discouraged, for his sake..." (Laura).

However, this may also be related to cultural expectations of a mother's role (see 5.3 'value & centrality of motherhood') within Italian society. The desire to be as involved as possible with their children, even when it exacerbated their symptoms, was viewed as a usual aspect of motherhood:

"Really, I don't know how else to live with it, if I don't try and do the most I can for...for them above all else! I'd rather miss out on something and know that I've

done something for them instead of the other way around; just as most mothers would, I believe, in the sense that it's normal to make sacrifices for you children".
(Ottavia).

Women compromised their feelings of physical well-being, which they saw as something that was expected as part of their mothering role. Although it could be considered that all mothers prioritise their children's needs above their own, for these mothers living with MS they did this even if they then felt physically unwell afterwards.

Both Ottavia and Sonia rationalised the modifications their children had to make to their lives, as increasing their realisation of the world around them.

"I say that I can't do certain things but maybe for her it's something that helps her understand that the world isn't perfect... I think that all human beings have their limitations and it's not like they can do whatever they like, I am included in this"
(Sonia).

In the above quote, Sonia demonstrates her belief that although she is not able to physically participate in all the tasks that she would like to, no one can do everything they like, regardless of whether or not they have MS, and everyone is limited in one way or another. In discussing how their children had modified their activities, women also spoke of how some tasks could just not be adapted to enable them to participate with their children, but that their children learnt to accept this in the way that all children learnt to accept that there were confines in life.

“so they too have to accept it as something they can’t do, you don’t do, like when someone doesn’t have the money to buy a Ferrari and so they don’t do it, like that...” (Ottavia).

When discussing relationships with their children, a key issue was around communication and for women who knew their diagnosis before becoming pregnant, or whose children were very young when they were diagnosed, there was more likelihood to be openness in communication about MS. Women aimed to deter any courtesy stigma for their children, although this did not necessarily mean that they did not feel stigmatised themselves. This issue of stigma is therefore relevant both to the women’s self-identity and to their relationships with their children.

Other issues regarding relationships with children were around how children adapted and assisted with tasks, and how women were able to participate in activities with their children. When physical barriers meant that, despite their best efforts, the women were still unable to participate in activities with their children, they often delegated these to others. In this way again the women were showing how they made sacrifices by handing over part of their mothering role to other people. How women felt about this will now be discussed.

6.5 Shifting of Roles.

As well as discussing how their roles with their children could be modified, there was also evidence that the roles between some of the women and their husbands had changed.

Many women spoke of how, when they were unable to participate in some aspects of

their children's lives, they delegated to others, often their husbands, to a greater or lesser extent:

"her father looks after her and she's okay...and that's what's important to me"
(Francesca).

For some this seemed to be the natural thing to do, and Laura and Maria both commented on how they took a pragmatic approach to delegating tasks to their husbands.

"I have to think about what I can do and what I can't do...and it's obvious that if he wants to go for a bike ride my husband should take him" (Maria).

Rather than viewing that if they had some support it could enable them to do more activities with their children, Maria and Laura accepted that their husbands would do activities with their children instead. However, even though the women could see the practical side of delegating tasks, it could still cause frustration for some.

"I want to go up there and help them, I mean, I want to wake them up! I know that they have to go to school, one to nursery school and I want to be there, I want to go up there, dress them, brush their teeth..." (Ottavia).

Alessandra too, although she spoke openly about the amount of practical support that her husband and family gave her with childcare tasks, expressed sadness that she had to delegate tasks to her husband, which sometimes made her feel that her role was superfluous:

"yesterday evening it was one of those nights and her dad came, he brought her bottle, the milk, after I'd read her a story, I was there beside her bed...'Mummy, go away!' because...I don't know! Because she wanted her dad, she didn't want her mum and...and her mum went away! What should I do? Should I make her cry? No!...she, when...sometimes, I think that perhaps it would be better...I don't know,

if I...perhaps if I didn't have health problems and I could care for her more!...to be with her more and so she...[restrains her tears]...and so...she wouldn't call 'daddy', she'd call 'mummy'...like most children, right? [sobbing]...instead, she asks for her dad...what should I do?...that's the way it is!" (Alessandra).

The intensity of the emotion that Alessandra expressed when telling this story, shows how upsetting she found it that her daughter had asked for her father rather than her, when she was doing her utmost to retain an active role with her daughter. In fact, although Alessandra similarly to other women had delegated tasks to her husband, her comments show that she felt she had lost part of her mothering role. A sense of 'loss' was discussed under the superordinate theme of 'Self and identity', and this example also shows that losses in activities the women were able to do with their children impacted on stereotypically defined gender roles. So whilst on a practical level the women could see the benefits of delegating tasks to their husbands, this was a personal sacrifice for some, and induced a sense of loss of role.

As mentioned earlier, Fiorella was the only woman in the study who was not living with her husband. She therefore was unable to delegate tasks as other women had done and she expressed that she would have relied on her husband, had he been there, suggesting cultural expectations of a two parent family being the norm.

"Jesus Christ made us have children in two, so there needs to be a mother and a father! [the woman] shouldn't count on anyone's help, except her husband's! That's necessary for having children! I'm speaking from experience..." (Fiorella).

As well as Fiorella, Alessandra also spoke about the importance of having a reliable husband or partner when making the decision to have a baby, as a woman with MS. This

approach to a more traditional family construction was also reflected by Alessandra in thinking about her relationship with her daughter in the future:

"And we were also fortunate in that respect! Because we had a baby girl! Because, in my opinion, as she grows, my daughter, especially in my case, I'll need...my daughter...I'd be sorry for a son to have to look after me...one thing that I often think about is that I'm sorry that I will have to cause her the inconvenience of having to help me...because, unfortunately, that will be the case!" (Alessandra).

Although Alessandra expressed some sorrow that she would depend on her daughter to look after her in the future, she indicated that it was better that she had a daughter rather than a son, as she perceived it was a more natural thing to expect a female to offer such support. Leona too, who only had a son, talked about her concerns for the future and how it would impact on her son's life as an adult:

"If and only if I get worse, I'm sorry that my son...will also finally feel a bit of the situation, because, after all, then...I'm still his mum! And then, you understand, the thought will come to his mind 'I have to take care of her!' and I'm afraid of becoming a burden to my son!" (Leona).

As well as this more traditional view of the role of sons and daughters, it is interesting that there was also apprehension around adapting the roles of husbands with reference to a more traditional gender division of roles. Maria told us:

"I suffer because of that as well, because I see my husband who, I dunno, has to prepare food sometimes, he makes the long journey home, sets the table, because, you know, at fourteen, fifteen year old girls are a bit...I remember how I was...but

uhm, I was like that but I had my mum who did it, now, I can't do it and I'd like it if my daughter helped out a bit, helped her father too...because he comes home, makes dinner, eehhh...that's a problem too because, another time he'd plugged in the iron so he could iron one of this shirts, he needed [breathes] eh, it's a mess [very quiet voice] it's a mess..." (Maria).

Maria shows her distress that her husband has had to take on tasks that she sees as being her role, with tasks like homemaking considered a female rather than a male role, and that her daughter should be assisting with these tasks, rather than them being done by her husband. This example and those feelings expressed by Alessandra, reinforce the gender division of roles often passed on to the next generation by expecting females rather than males to take on household tasks and caring roles. Because of these socially constructed and culturally defined roles, some women struggled with delegating tasks to their husbands and often instead relied on parents or other relatives for support. Involvement of family members in assisting with childcare and household tasks was common to all the women in the study, be it husbands or wider family members and how the women felt about asking for and receiving care was a subject often discussed.

6.6 Asking for and Receiving Help from Family.

All the women in the study received some level of practical support from their immediate family members and the way in which this support was offered was generally spontaneous and seen as a natural part of family dynamics. However, for some women, they could not rely on assistance from their wider family members, as either their families were not as forthcoming with support, or were not around to offer this. For a few women, support could feel a little overwhelming at times, due to its intensity. Some

women told us that their families failed to understand their MS, which affected the relationships between the women and their families. Another significant concept that arose was with regards to how a family was defined and how this impacted on support. A number of women had moved into the area to be with their husbands and had left their “family” behind in their original home. Rosa was married with two children, but still referred to her family as being in the south of the country. Cristina had moved from the south of the country to be with her husband and perceived therefore that her “family doesn’t live near me” as her biological family had remained in the South. Because of this, Cristina told us:

“so, obviously, I couldn’t count on my family for help because they are far away [and] because of this I have always....mmm...I have had to manage on my own in a way” (Cristina).

This physical distance between the women and their families would impact on how family members could assist, if they were not living locally in order to be able to do this. One example of how family members did assist was given by Erica. Having lived at her mother’s house for the first year of her children’s lives and receiving a high level of on-going support from her mother, she told us:

“I think she’d have done that even if I didn’t have MS! I mean, because any mother, I think, would give her children a hand...either with multiple sclerosis or without, I think that all mothers in the world would!” (Erica).

There was therefore a natural assumption that family members would intervene as and when required, whether disability affected them or not. A number of the women lived in very close proximity to their family, some in the same building or street, and many had

day to day help from their parents or extended family members. For Patrizia, the proximity of her parents was of benefit to her as she told us:

"I often need them...yes, to help me, they accompany me when I have to do the shopping...sometimes also to go for a walk, because without them, without them I couldn't do it on my own!" (Patrizia).

For many women, their families stepped in to help spontaneously and they did not doubt the willingness or appropriateness of asking families for help.

"I've never had problems, mostly because I don't need to ask people...they come to help of their own volition...but I didn't feel bad for asking, because I knew that whoever I asked would never say no..." (Elisa).

This natural provision of assistance from family members was discussed by women across all three groups. This demonstrates that it was not just the women who had a greater degree of physical impairment who were assisted by their families, but that interfamilial support was common place. This support was from parents, parents-in-law, sisters and cousins, indicating that the existence of the extended family remains the norm in this cultural environment, regardless of disability. Although again most women viewed support pragmatically, seeing it as necessary in order that they were able to meet their children's needs, for some there was still an element of regret that support was needed. There was also a link between those women who indicated they were battling to "maintain control" of their MS, and their reluctance to ask for and receive support. Patrizia told us that she had a large amount of support from her family when her children were younger and although she spoke of wishing she could manage without assistance, she accepted that her situation meant that she needed support, which was given by her

family. For some women, help from families was not spontaneously forthcoming and asking for help was difficult, even “humiliating” (Julie) for some. Some women spoke of how they pushed themselves to do as much for themselves as possible, sometimes only asking for assistance from others as a last resort.

“mmm, I ask for help when I am really...when I’m desperate! If not, I do it myself! I always try to manage! But when I’m not well I because I can’t...I can’t do it, eh, I feel like a person who is...you know, you’re reminded that you are ill anyway!”
(Laura).

Asking for help was not necessarily easier for women with more advanced MS, who had more physical difficulty in their ability to independently carry out tasks. For example Cristina told us that she found it difficult to ask for help, even from close family members.

“I find it very hard to ask for things, I always have, so if I ask you to do something it’s already quite an effort for me! The second time I have to ask it requires double the effort!” (Cristina).

Ottavia told us that she did not always think to ask for help, as she carried on doing everything she could for herself, however when help was offered, she was pleased to take it.

“...when someone offers to help me I don’t immediately think, no, I should do this by myself...I don’t find it humiliating or...it makes me happy when someone tries to be useful, anyway, tries to help me...it’s not something that embarrasses me...or that bothers me, quite the opposite!” (Ottavia).

As women were often reluctant to ask for help, or just carried on with tasks, they sometimes felt that their families did not appreciate the effort it took to do these tasks:

“Today I feel better, so I want to do, I say, today I want to do something! I don’t know...I want to get rid of the dust in the sitting room. And I dust the sitting room and I Hoover the velvet seat! They [her children] come in...they throw their things on the table! ...and I say, I’ve been working all day! It took me the entire morning to do something that I used to do in half an hour! So sometimes it’s a hard thing! Tough because, anyway...I don’t feel that I am understood... (Cristina).

Although many may recognise the frustration of inconsiderate teenager behaviour, this quote from Cristina is particularly poignant as it represents the effort it has taken her to do a task and her pleasure at having the energy and motivation on a “good day” to do something like this and the disappointment that her family were not able to recognise this with her and appreciate the strength it took for her to complete the task.

For other women, well-meaning encouragement from family members left them feeling that they were not understood. Maria gave us an example of when she asked her daughter to help her write the shopping list and her daughter responded:

“...‘can’t you do it your—...sure you can! If you try hard, you can do it! If you put a bit of effort into it, sure...’...Then we fight because when people say things like that to me, it upsets me and...or when people tell me when I can’t do something, when I really can’t do it, to ‘put in a bit of effort into it!’ what is this ‘effort’? Even from when I get up in the morning, for me it’s an ‘effort’ getting out of bed, but I do it! I have to do it, I do it!...for you, it’s a normal thing, for me it’s not! [breathes heavily]” (Maria).

For others, asking for help was difficult due to the needs of the people they were asking for help from, and both Fiorella and Francesca, who were women with more advanced MS, had to ask for help from their elderly parents. Other women stated that they were reluctant to ask for help because of their parent's own health and wellbeing, as well as their age:

"despite the fact that she was unwell herself and she had problems too, she still always came, I mean, at the end she forced herself. I, sometimes, at times she'd call me and she'd say 'if you need me, I'll come', especially in her last days when she was really unwell...'if you need me I'll come' she'd say, and even though I wished she would, I'd say 'no, don't worry, everything is fine, don't worry, stay at home'..." (Delia).

In this way, by declining her mother's offer of help, Delia was sacrificing her own need for support, reciprocating the sacrifice her mother was offering to make for her. Her mother's willingness to help, despite her own illness reflects the cultural expectation that families offer support to each other. Intergenerational support, in terms of the women receiving help from their parents was common amongst the participants in my study and there was also a common expectation that children would also assist with tasks. This aspiration to create a cohesive extended family set-up demonstrates the close family ties incumbent within Italian society.

As indicated earlier, all the women to one extent or another, had help with some aspect of their mothering role from family members, be it husbands, parents, or their children (see 6.4 'relationships with children'). Although women were generally very accepting of support from their families, assistance could sometimes feel overwhelming. Both

Alessandra and Patrizia spoke of their gratitude to their parents for their support, but also said that this came at a cost as consequently they had no time to themselves. Perhaps because of the level of the support she had, Patrizia told us that she was irritated by her husband, although she did not feel it was because of anything he had done:

"I know that he has nothing to do with it, but unfortunately that's the way it is, I know that whatever he does will annoy me, I feel like he's always hovering around me and I tell him – I'm not a dog on a lead!" (Patrizia).

The analogy Patrizia makes to being like a dog on a lead suggests she feels that she has lost control and that she is restricted. The intensity of support from family members could lead to women feeling they had lost their autonomy and their full role as mothers. For Fiorella, support from her parents in law when her daughter was young suffocated her own role as a mother. She said of their help:

"...it was too unhealthy! When I started to see that [my daughter], given that she was always there, was calling her grandmother 'mamma'...I took her away from that environment" (Fiorella).

In contrast, Alessandra had managed to maintain some control over her support:

"...my husband often makes fun of me and says 'you sit there, on your throne!' he jokes about it! Eh [laughing] it's true! It's true, I'm here, then I'm also very picky! I've always been very picky, so I want things done in a certain way, so I can be a pain in the behind, a big one, they say!...that's the way I am! That's the way I am...I direct!" (Alessandra).

So although Alessandra was one of the most severely impaired women who had a high level of support from her family, which at times she told us could feel overwhelming, she maintained an active role in controlling and directing the support she had. This was perhaps because her family had a good understanding of her condition and how her symptoms affected her, as Alessandra took an open approach in communication.

However some women spoke of how their families did not really understand their condition or were dismissive. Three of the least impaired women, Sonia, Leona and Delia, spoke of how they had struggled to get their families to understand their MS and Delia, due to their lack of understanding, had stopped discussing her MS with her wider family:

“mmm, I don’t talk about my disease much, very infrequently, with anyone, especially with my in-laws, we don’t talk much about it, in fact we almost tend to hide...and I pretend it’s nothing, anyway...anyway I can’t change how people are. I don’t know why, it must be ignorance...I don’t know, I don’t know what it is, but...I’ve given up! I know that’s the way it is, and that’s it, even if I get upset, it won’t change anything, then, in the end, that’s how it is...[long pause]” (Delia).

For two of the women, Ottavia and Elisa, a lack of understanding from their family had led to them losing contact with a parent following their diagnosis:

“I have a dad who disappeared when he found out about my disease, so he practically doesn’t exist anymore” (Ottavia).

This lack of understanding from family members may be related to how the women were living with hidden impairments. It is relevant to consider that three of the women quoted above, Sonia, Leona and Delia, also spoke about hiding some aspects of their MS.

Whether the lack of understanding of family members had led to them hiding their MS or whether families did not understand because the women were not more open about how

their symptoms impacted on their lives is not clear. Delia told us that she had tried to explain to her husband how her symptoms influenced her day to day life.

"I have also struggled to make my symptoms understood, my disease understood, to my husband, because he didn't accept it...and I don't know when, exactly, he did come to accept it. I think that it seems to be going better now...but, until not too long ago...it was hard because he didn't...he didn't accept it, so...we often fought about it, because he didn't understand my limits...and it's not like I have fun not doing something, it's not because I don't want to do it, but because I can't..."
(Delia).

The lack of understanding of Delia's husband may link to the gender stereotypes of family roles previously discussed, and his fear that these would be jeopardised if he acknowledged and accepted Delia's condition. In this way, fear of challenging socially constructed roles and relationships relates to the fear of stigma associated with disability. If a woman is disabled, she may need assistance from someone else in order to fulfil her role in its entirety, which may fall to the husband, so challenging typical gendered role divisions. In relation to this, two women told us that they had doubted whether their husbands or husbands-to-be would wish to continue their relationship in view of their MS. When Silvia was diagnosed, she questioned whether her husband would continue with their marriage, as she was advised not to have children. Alessandra too told us:

"and that made me happy, knowing that my fiancée, despite my disease, had decided to build a life with me" (Alessandra).

6.7 Conclusions on Relationships with Others.

The above analysis has revealed how MS impacts on the research participants' relationships. The women spoke about the importance of their friendships and how they relied on friends for practical or emotional support, or for companionship. However this was not always forthcoming and could lead to feelings of loss. The impact of MS on the women's relationships with their children varied, and often depended on the age of their children either currently, or their age when their mothers were diagnosed with MS. There was compassion and natural assistance shown by younger children, particularly when their mothers had either known their diagnosis prior to having children, or when the children were young and the women had consciously been open in communicating how their symptoms impacted on them from an early stage. This was not always the case with older children and though women who spoke of teenage troubles tended to associate this with normal teenage behaviour, some women had difficulty monitoring their teenagers, due to environmental barriers or fatigue. Despite the spontaneity of family members to step in and provide assistance, there was an emphasis on gender defined roles, with some women having difficulty delegating to husbands and relinquishing some typically female defined tasks. This impacted on how the women saw their future with regards to their children, with a tendency to see daughters as being those to whom future care and household responsibilities would fall. Although all the women in this study had some level of assistance from their families, they did not perceive that hands on practical support from the state was necessary or valued, instead preferring to rely on family members for assistance, or employing their own home helps. This issue of external support is discussed within Chapter 7 under the superordinate theme of 'Challenges and support within society'.

Chapter 7 - Challenges & Support within Society:

"You're marginalised! They don't pfff...it's almost seems as if it is your fault...also because it's a disease that, in my opinion, still isn't...mmm is only known in its serious form!...they see you as if you're already in a wheelchair!" (Leona).

The above quote typifies the reported lack of understanding about MS and issues concerning disability, and how some women felt ostracised on account of having MS. These issues arose from the third superordinate theme identified, which is 'Challenges and Support within Society'.

Figure 7.1 Superordinate Theme of 'Challenges and Support within Society' & Underlying Sub-themes.



This overarching theme explores the women's experiences of interactions within society and includes how the women perceived society treated them, and the attitudinal barriers they faced. Many women spoke of how they felt society was ignorant about disability issues and about MS as a condition. Some also spoke however about how it was only the realisation of living with MS that had increased their own awareness of such issues and how they concluded that others in society, including those in influential decision making positions, would also lack awareness of the issues for disabled people as they had no direct exposure to life as a disabled person.

Other issues that arose concerned physical obstacles to participating in the social world, such as environmental barriers or transport issues, and social elements, like finances. Such factors impacted on how the women were able to socialise and participate in the lives of their children, but also how they were therefore put into a position of dependence on others, due to the lack of accessible facilities. Another significant part of the women's experiences as mothers related to the medical influences on decision making around pregnancy. This was perhaps most relevant to the women who decided to have children with the knowledge of having MS, who discussed this with their doctors prior to embarking on having a child. However, it was also applicable to the women who had not been diagnosed with MS, either because they had been diagnosed with a different condition, but also for those who had some symptoms but had not been diagnosed with MS. Firstly, resources will be discussed in terms of externally available support and the women's views on this. The level of impairment of each woman is especially relevant to consider within a chapter that incorporates environmental factors and attitudes of others, therefore the impairment group each woman belonged to will be referenced after the quotes. As an aide-mémoire, the impairment groups are:

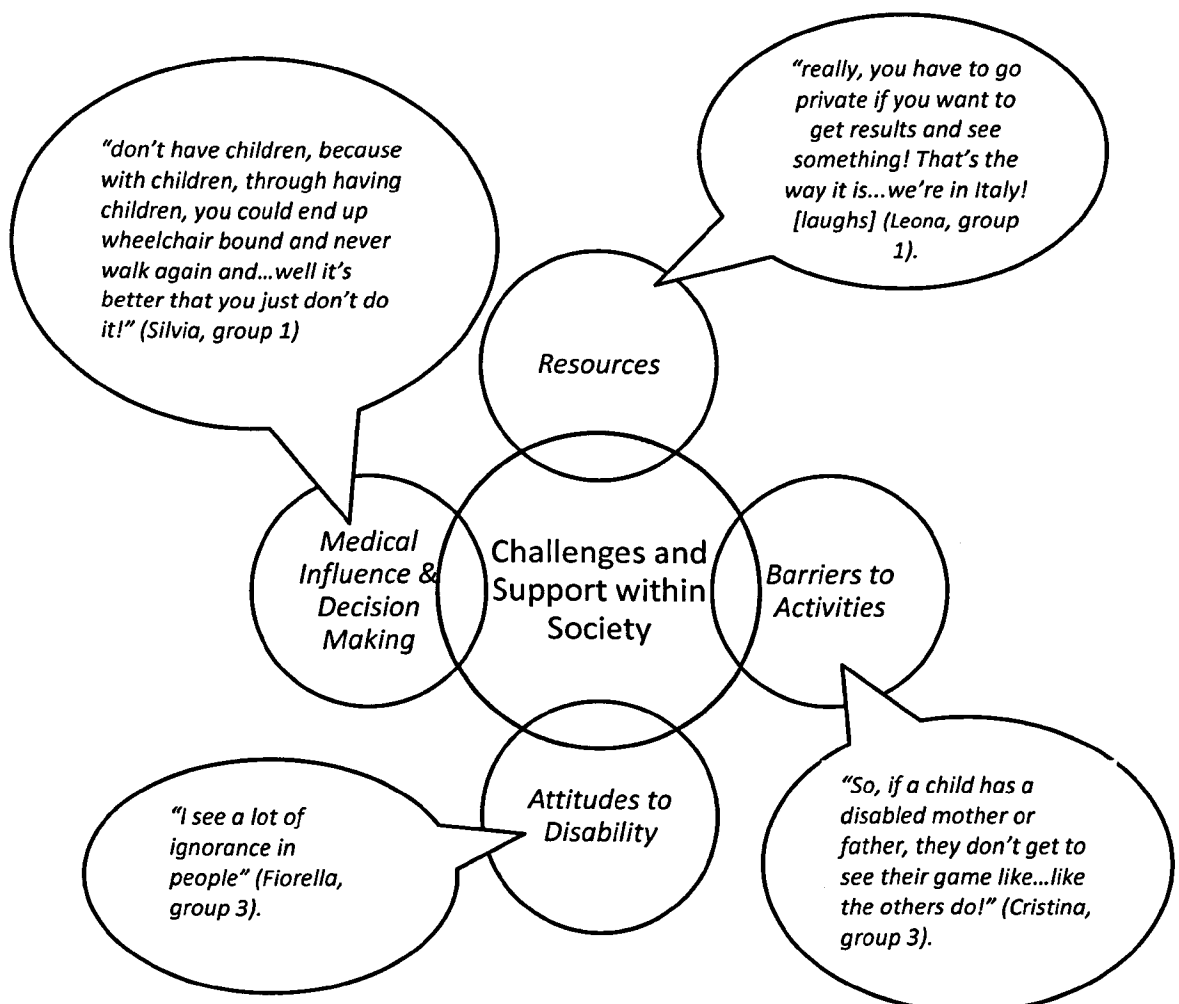
Group 1 – women with a diagnosis of MS, who have some level of impairment which impacts on their everyday function. This group incorporates women who are still mobile without aids, but are borderline for needing aids to assist them with everyday tasks.

Group 2 – women who have a greater degree of physical impairment, which regularly impacts on their everyday function.

Group 3 – women who are severely physically impaired and are regular wheelchair users.

The diagram below demonstrates the sub-themes within this superordinate theme and a representative quote to support the identification of each sub-theme.

Figure 7.2 Representative Quotes to Demonstrate the Sub-themes.



7.3 Resources.

The sub-theme of ‘resources’ captures issues around the availability of financial and practical resources, and the women’s feelings about accessing such resources. For women who needed hands on support with care, many had recruited private support workers, although some women with lesser impairment resisted engaging external support, seeing it as a sign of dependency. Sonia (group 1) was reluctant to accept help and told us about how her doctor had commented on the infrequent help she had at home, encouraging her to increase her support, but for Sonia, needing help was indicative of limitation.

“..when someone is disabled or old, they are limited! And no one likes limitation right?” she continued “But having to ask for help is never a nice thing” (Sonia, group 1).

Sonia’s view relates to the stigma she felt at being a disabled person, (see 5.6 ‘stigma and disclosure’). By linking “requiring help” with “limitation” she suggests that help is not facilitative to independence, but indicative of being unable to cope. Rosa too, another woman in group 1, saw that if she employed help then it would be tantamount to dependency, thereby increasing the stigma of being a disabled person. When her husband suggested that they employ a cleaner, Rosa responded:

“I don’t want one, because if we get a cleaning woman, I’ll feel even more like an invalid and I’m not one!” (Rosa, group 1).

Whilst Sonia and Rosa spoke of their reluctance to accept external help, a number of women did employ private help, particularly those whose MS was more progressed than that of Sonia and Rosa. Fiorella and Ottavia (who had a greater degree of physical impairment) were the only two women who received practical care support from

statutory services. However, this support was not always sufficient and Fiorella had contacted social services to ask for their help with managing her daughter's needs, but it had not been forthcoming.

"Social workers like that are useless! I understand that they have a lot of work, however, honestly, when you're confronted with a mother who is asking you for help, who is disabled, who is like this, with a daughter who is like that, who has to live with what she has to live with...I hoped they would help!" (Fiorella, group 3).

Fiorella's experience suggests that approaching the state for support was futile and this view was supported by other women who had chosen to employ their own private help, rather than expecting the state to provide appropriate assistance.

"really, you have to go private if you want to get results and see something! That's the way it is...we're in Italy! [laughs] (Leona, group 1).

Perhaps because of the realisation that state support would not be forthcoming, or not appropriate, there was a reluctance to ask for state support. We asked all the women about the support they had and whether they felt any support was required but not delivered, and no one suggested that the state had more of a role to play in providing hands on care or support, other than the above example from Fiorella when she had asked for help with her daughter. Two of the women mentioned that increased therapy support would be helpful, and a few suggested the state should provide more financial support, in relation to the disability pension, or the lack of financial recompense for women who had to give up work because of their MS.

"I had to leave [my] job and so...at a financial level, assistance...would have been nice in the past and also now..." (Silvia, group 1).

The process for deciding on entitlement to a disability pension in Italy is based on a medical model of disability, with people being assessed and allocated a "percentage of disability", based on their level of impairment. This reinforces the stigma associated with being a disabled person and the implicit shame attached to presenting oneself for medical judgement. Even for the women who were the most significantly affected by MS, the process for applying for a disability pension was a demeaning experience.

"I've only had, as standard procedure, a disability evaluation and requested my disability pension and that's it...I didn't ask for anything else...mmm...it was hard enough for me to even do that! [begins to laugh] rather than ask for something..."(Cristina, group 3).

This may explain why many of the women did not ask for any support. The process of applying for state support and benefits is derisive, and does not address the barriers that my participants reported, instead focusing solely on their impairment. However, there was also a fundamental view that family support was more valued in any event, reflecting the interdependency between families in this cultural context, as discussed in the literature review, and evidenced in the previous chapter.

"I think the type of help that I need is from the people who are close to me..."Institutional [support], nah, in my opinion, family members above all else! I think that the family context is important!" (Laura, group 2).

As well as a lack of state funded support with care, there was also a deficiency in the provision of appropriate assistive equipment for some women. Ottavia had ended up buying her own walking frame as the one she was supplied with had faulty brakes. Although she had sent it back for replacement, four years later it had still not been returned. This lack of equipment provision was also reported by others in the study, both in relation to availability of equipment and funding. Maria told us that her wheelchair had broken and she had asked for a new one, but:

“they called me at home and a doctor has to come see me, who still hasn’t come by, who must ‘come and see if you really need it’...and I feel...when I hear that sort of thing, I feel bad! And why do they have to come and check first? And [my private carer] said ‘oh don’t make such a big deal out of it! We are fortunate that we are able to get one!’ It’s madness!” (Maria, group 2).

Again Maria’s experience alludes to the stigma of being a disabled person and societal attitudes, when asking for what might be considered to be basic resources to facilitate her independence. Questioning her entitlement to equipment reinforces a position of marginalisation for her, suggesting she is untrustworthy and the opinion of a doctor was needed to validate her request. Ottavia told us this reluctance to give disabled people what they are entitled to was also reflected by public opinion on giving assistance:

“I was on Facebook and I saw a comment that said that people or families should take out personal disability insurance from banks because the state cannot support them and...I was hurt!...Because you know that you’re not a burden, in the sense that, you know what you’re asking for now and what you’re being given is something you are entitled to...and instead that’s definitely not how it is, both from an institutional, the state’s, point of view and sometimes even from other

people's point of view. It seems that they make you feel almost like a burden..."

(Ottavia, group 2).

Attitudes such as the one reflected in the above quote reinforce notions of stigma in being made to feel an encumbrance on society, when asking for rightful entitlements. Eligibility for disabled parking and parking badges was mentioned by a number of women and some had taken measures to manage the lack of provision.

"I don't have the disabled badge, the symbol that designates you as disabled and, in my opinion, they'll never give me one! Because when they see me, that I can walk...So, what you do is you park, and you get fined and you pay the fines, I tell you I have a budget of 300 euro a year for fines, I don't have a garage, I need the car often in order to do things and a [small] contribution is enough! I don't complain about it! I try to be pragmatic" (Sonia, group 1).

Despite the fact that she was very limited in her mobility, Sonia had accepted the fact that she would not get the disability badge to enable her to park where she needed to, and assented to paying fines that should not have been necessary. However, whilst this might not create unmanageable financial difficulties for Sonia, as she was still working, the financial implications and lack of appreciation of others that disabled parking spaces were not only there for convenience, but also for financial reasons, was articulated by Ottavia:

"And that's what people don't realise when they criticise disabled parking! It's not just that perhaps I'm disabled, I'm missing a limb, I'm in a wheelchair, I can't walk, and so I have the right to a parking space, but that I can't afford to pay for one every day because I live on a pension and I can't do it, I can't manage...." (Ottavia, group 2).

There was a reluctance to challenge the lack of formal financial and practical support, particularly from women in group 1, who were less impaired. Instead despite their dissatisfaction with the poverty of resources, women found coping strategies. For those with a greater level of physical impairment, there was an emerging sense of unfairness, even though when the system was challenged, there was little satisfactory resolution. As well as the lack of financial and practical support from the state another restrictive barrier for the women was in connection with environmental issues.

7.4 Barriers to Activities.

An issue raised by many of the women, regardless of the level of their impairment, was the environmental barriers that impacted on their ability to access activities with their children, including schools, sports activities and leisure venues. This was because of the architectural barriers, including a lack of lifts and uneven pavements; and physical obstacles, such as obstructions in shop entrances and inaccessible transport. Although these architectural barriers were mostly of concern to women who used wheelchairs for mobility, they also caused some problems for women who used sticks to walk with or who had other mobility problems. All of the women in group 3 and group 2 spoke of how architectural barriers impeded their access to activities. This could be in relation to general problems with mobilising around their local environment, but also specifically with hampering the women's involvement in their children's activities, to the extent of not being able to access their children's schools. Even for women in group 1, whose mobility was less impaired, there were problems with accessing children's schools.

*“there are two huge flights of stairs [at my daughter’s school] and there’s no lift”
(Silvia, group 1).*

When facilities in schools were available, they were not always appropriate:

“...then inside the school it’s another issue because there are stairs...and the wheelchair won’t fit in the lift...it’s a big problem! I went there with my walker last year, but also...without my wheelchair...I can’t go anywhere...unless my husband...[laughs]...in his arms...” (Maria, group 2).

As Maria’s comment indicates, the lack of accessible facilities forced many women into positions of dependence on others to assist them with access. This was raised by other women, who either relied on husbands or relatives to take them to venues, or ended up not being able to go at all. Environmental barriers therefore impacted on the women’s abilities to fully participate in their mothering role and linked to feeling of ‘loss’ and ‘shifting of roles’ as discussed in other sub-themes.

Environmental barriers therefore precluded women from attending activities, but had a wider impact on the ability of women to fully engage in their children’s lives by limiting communication with other people who were involved with their children. This was not only teachers, but also included their children’s friends and the parents of other children (see 6.3 ‘friendships’). For some women with teenage children, access issues meant that their parenting role was restricted, and impacted on how they were able to care for their children in the way that they would choose to (see 6.4 ‘relationships with children’). For example Fiorella told us she was unable to get to venues her daughter went to.

"I can't keep up with her as much as I'd like, in the sense that...if I can give the example of following her when she goes out, be a 'detective-mum' to see if, for example, I don't know, if she smokes, if she hangs out with friends who smoke, if, for example, I don't know, they go to a bar and instead of getting a hot chocolate, she gets something alcoholic, because you have to consider that, because friends matter a lot!"(Fiorella, group 3).

Aside from accessing their children's schools, which a number of participants told us they were unable to do because of physical barriers; other simple and everyday tasks that parents ordinarily engage in with their children were obstructed for many women. Issues such as this also impacted on 'relationships with children' as parents of older children were prevented from participating in tasks like clothes shopping, which would be a typical mother and child activity at this age. Maria gave us an example of this:

"she wanted me to, I dunno, have a look [in a shop] and I said to her 'How can I? How can I get in? Because you've seen me, there's a pole in the middle of the [shop] entrance!' I don't know what the stupid thing's doing there, I don't know! But I can't get in! I mean, it's the perfect width that I can't get by! And there too, she either goes by herself or..." (Maria, group 2).

Maria was one of the women who had delegated tasks to her husband (see 6.5 'shifting of roles'). However, it is clear from the quote above that environmental barriers contributed greatly to her having to delegate this activity to her husband and that her involvement in activities with her children was restricted by external factors, rather than due to her MS symptoms.

Cristina, who was one of the women with the most significant impairment, had gone to great lengths to continue to participate in activities with her daughter. She had obtained an adapted car and a special licence to enable her to resume driving, but found that additional barriers were present, for example when she had managed to drive her daughter to the swimming pool. Whilst the other mothers were sitting on the viewing terraces at the pool, which were inaccessible to her in a wheelchair, the staff suggested she instead be helped by them to climb onto the first step and sit there. However, someone intervened and she was 'allowed' to sit by the side of the pool instead. Cristina saw the positive in this and said to her daughter:

"You see? The other mothers are in the terraces. I didn't think I could even come, but I'm here and I can see you up close!" (Cristina, group 3).

Although Cristina had rejoiced in this situation for her daughter, seeing it as a bonus that she got a better view, she was still singled out as a disabled person, because the facilities available to other parents were not accessible to her. She faced the choice of having attention brought to her either by being assisted to clamber up onto the first step, or by sitting at the side of the pool. The alternative was for her not to attend at all, which was the case for other women, who had no choice but not to attend their children's activities. Elisa told us how she was unable to access her son's scout group:

"getting there, for me is imposs...[ible] especially because, as you may know, it's true that Genoa is...I mean, there's no bus for the disabled and ...we're not in Switzerland!" (Elisa, group 3).

Elisa's remark relates to her problems getting to a venue, which was commented on by women with less mobility impairment, indicating that it was not just women who were

wheelchair users who had access issues. Even when new structures had been built, there were still issues of inaccessibility for women with mobility impairments:

“because even walking there, now they’ve made a new road...but there...I mean, it’s difficult for me to go...because, anyway, I fall...I fall because the pavements are awful! The new road is awful! I always fall, and, anyway, when I go out, I never go out on my own, I always have either my stick or my walker if I have to walk more than a little bit...and I lean on someone who has to hold me up, because if not, I fall! So, architectural barriers...pfff! My god! There are so many! Really...” (Patrizia, group 2).

Again Patrizia’s example shows how inadequate facilities had contributed to her dependence on others to assist her with accessing the local environment. Even when facilities were available which should assist women with mobility difficulties, they often did not work or were not suitable. Fiorella found that the lift in her apartment block was often broken or vandalised so she was unable to use it, and Alessandra confirmed the problems with unusable facilities:

“Even when there is a wheelchair ramp, there isn’t, because everything is broken” (Alessandra, group 3).

However, despite the lack of suitable accessible facilities, there was also a resigned acceptance of the situation. For example, in response to being asked whether there was a lift in her daughter’s school, Julie said:

“Nooo...we’re lucky there are stairs! Ehh...let’s not ask the impossible!! Then, considering how schools are these days! Let’s not hit that sore spot no! There are

stairs, ok, that's enough! I mean, yes, I mean...there's a stair lift for wheelchairs, yes, but it doesn't work, obviously! That's normal..." (Julie, group 2).

Measures to ensure that facilities were kept in a usable condition or were suitable in the first place were absent, and many women expressed frustration that other countries appeared to be able to provide suitable wheelchair accessible facilities, but Italy could not, and they made comparisons between Italy and other European countries.

"...it's those little things that you can't do because there isn't a structure, there isn't...there aren't things that enable you to!...At an institutional level, there is a sea of difference between Italy and other European countries" (Ottavia, group 2).

This issue is discussed further within the 'attitudes of others' sub-theme below, which highlights this reference to the institutional disregard for ensuring appropriate facilities for disabled people are provided. Because of the deficiency in facilities which precluded many women from attending activities with their children, some found strategies to continue to make them feel involved even when they could not be present. Elisa shared notes with the scout leaders and Ottavia told us that she gave her daughter a small personal item of hers to put in her pocket:

"so that she knows that I'm there with her, that even when I'm not there, I'm there – a small part of me is... So, I experience many things in a more detached way, but...I experience them" (Ottavia, group 2).

Through doing this, Ottavia was able to feel included in activities with her children albeit in a more detached way. Although she was unable to fully participate, she drew solace from her ability to maintain some involvement. As discussed earlier, women went to

great lengths to ensure that their children did not miss out on activities (see 5.7 ‘feeling different’ and 6.5 ‘shifting of roles’), even when this caused increased difficulties for them, and this was further exacerbated by the environmental barriers that the women had to deal with.

As well as access into buildings, another restrictive factor was getting to the buildings, with the vast majority of women being unable to use public transport, because it was not equipped suitably for their mobility impairments. Alessandra and Ottavia compared the lack of accessible public transport in Italy to that in other countries:

“All the types of public transport [in that Spanish city] were wheelchair accessible...Because life there is much easier for people with disabilities. Why isn’t it so here?” (Alessandra, group 3).

Transport was an issue for many of the women, both in terms of the lack of accessible public transport, which necessitated women having to rely on others to take them to and from activities, which reinforced their dependency on others, but also emphasised the lack of freely available transport to hospital appointments. Maria and Silvia both had their free transport taken away from them, due to government budget cuts. Whilst many women spoke of their anger at the lack of financial support and the environmental barriers they faced, this anger was often repressed, for fear of causing further stigma for themselves or their children.

“I refrain from expressing my anger each time, because...in order not to cause problems for my daughter as well, because I don’t want to make her feel even more that she’s got a mother with problems whilst the other girls don’t!” (Cristina, group 3).

The one person who had challenged the authorities on accessibility issues was Alessandra. She had asked the local commune², to make adaptations to her daughter's school, so that she was able to access it. She told us:

"I don't often go to pick her up because, aside from the fact that on my own I couldn't get there, but even when I go with someone, there are the stairs to climb and it becomes a problem" (Alessandra, group 3).

Alessandra had been encouraged to raise this by another parent, who commented to her that he thought it was not right that she was unable to access her daughter's school, which had given her the final incentive to complain. Alessandra had suppressed her anger up to a point, but when supported by another parent, she had found the strength to challenge the authorities about the barriers she was facing. Alessandra had moved from considering the issues to do with access as being attributable to her impairment, to seeing them as a wider issue for society, recognising that it was the environmental barriers precluding her access to the school. This matches her description of her identity as a disabled person (see 5.5 'identity'), which sources the barriers to her participation in her daughter's life as being extraneous to her impairment. As it was gaining the support of another parent that convinced Alessandra to complain, how my participants viewed how others perceived them will now be considered.

7.5 Attitudes to Disability.

When talking about their lives as disabled mothers, a number of my participants considered how they had viewed disability in the past and commented that when looking

² Which is like a local council

back, they wondered whether they would have thought about disabled people and issues to do with access. Fiorella gave a particularly open account of this:

“to be honest, I think that I was responsible for the worst of that ignorance! Because when I could walk and I didn’t need the wheelchair, or things like that, it never even crossed my mind to go over to someone in a wheelchair and help them or push them...I saw it as a problem, I saw it as something that caused problems...So, I was worse than all the ignorant people and I think that, as they say, the tables have turned!” (Fiorella, group 3).

Fiorella’s account reflects the lack of consideration from others within day to day interactions that many of the women described. Alessandra told us that she felt this ignorance was caused by a general lack of awareness, rather than a deliberate desire to be oblivious to the needs of disabled people. From other participant’s accounts, there was a reported lack of understanding about MS and some women commented on the perception of MS as being synonymous with being a wheelchair user, with many of the other common symptoms not being recognised or considered by others. Other women had struggled themselves to comprehend their MS:

“...I mean, seen from your point of view, seen by you, because, I remember, it’s strange! Eh, I mean, to understand...my difficulty! It’s really strange, I mean, it’s really difficult, and I understand because I used to be...like you, and I think about how it was before and how it is now, and I understand that people don’t get it, I understand that, because I wouldn’t have understood either, if someone told me, you know, I can’t manage to iron. How is it possible that you can’t manage to iron? Pick up the iron and iron!” (Maria, group 2).

Maria's comment indicates her feelings of being different, (see 5.7 'feeling different'), but she is also suggesting that other people cannot understand how her MS affects her. This lack of understanding from others was also raised by Patrizia who wondered whether the fact that some of her symptoms were hidden contributed to the lack of consideration by those around her. She told us that her neighbours resented the fact that she had an allocated parking space and had had a meeting to discuss it.

"They don't understand the situation! Perhaps they look at me and I seem okay, but they don't know that I can't manage to walk! I mean, they don't know, they can't imagine, but...I dunno. Bad people! Bad and ignorant!" (Patrizia, group 2).

She implied that her hidden symptoms disguised her difficulties and that because she did not outwardly present as being disabled, others had disregarded her need for facilities to enable her independence. Julie, who was another woman whose symptoms were not outwardly very evident, told us:

"If I don't have my crutch right now, I walk really badly, like a zombie, then they look at me like I must be drunk or stoned! Because you have a sort of walk, a drunken sort of walk! And so...instead with the crutch, you're pitied!" (Julie, group 2).

Erica also alluded to her perception that walking with a stick would cause people to view her differently and this association between walking with a crutch or a walking stick, caused some women to disguise their difficulties, rather than use an aid to assist. Delia described being seen as someone who was drunk as she 'zig-zagged' across the street, and indicated that she preferred others to view her as being inebriated, rather than a disabled person, which indicates the shame and stigma she associated with being a

disabled person. The concern of presenting as being disabled by using a walking aid was raised by other women in the least impaired group. For Erica, her experience of walking without a stick had an adverse effect and she gave us an example of when she has accidentally bumped into a man whilst she was walking:

“he looked at me in such a way...I mean, as if I had shot him! I mean, have some patience! I said I was sorry, I didn’t do it on purpose...then surely you don’t know about my problems...” (Erica, group 1).

Erica’s comment suggests that had she been walking with a stick to assist her, the man may have been more understanding when she had collided with him. Silvia also commented on how she thought that using walking aids could engender more respect from others.

“if they see you with a crutch or they see you with a wheelchair, they might perhaps open the door for you” (Silvia, group 1).

However, for those who regularly used walking aids or wheelchairs, some spoke of how people stared or blatantly asked questions about their impairment, with women either responding with equal directness, or learning to ignore the looks of others. For women who were wheelchair users, some spoke of how they thought other people looked on them with pity. When telling us about how the pitying looks she had from other people made her feel, Fiorella said:

“At first I felt, not sad, but I felt...eh! I mean, I was aggressive, like ‘what the [bleep] are you looking at? What do you want?’ and now I just smile, I smile like this, so they understand the message: what are you looking at?! At the same time,

however, despite reacting with the smile, today I ignore everything! I mean, I live my life and that's it. I go past, I don't even look, I go along my way, those who want to say hi to me say hi to me, the people who don't, don't! Those who want to move out of my way, move, and if they don't want to move, I'll run over their legs with my electric chair! [laughs] I go about my way, and I think that at least you should be well-mannered!" (Fiorella, group 3).

Fiorella's account contrasts with the views of some of the women in the least impaired group who felt that outwardly presenting as being a disabled person may incur more respect from others. However, this was not necessarily the case, and the reactions of other people continued to reinforce stigmatising attitudes towards wheelchair users. Ottavia told us that she knew of people who would not ask for a disabled badge for their car as then they would be identifying themselves as being disabled, which they did not want to do.

A couple of women questioned whether this attitude towards stigmatising disability was more prolific within Italian society.

"Italian society is one of the worst societies when it comes to how they act towards [disabled people]...I mean, it's a lack of respect..." (Elisa, group 3).

Ottavia told us about a trip that she had gone on to Euro Disney in France, where she was given what she termed 'preferential treatment'. She told us that most people just accepted this, but for some people it was seen as strange that she was given this treatment and most of those people were Italians. This inclination to view facilities as a privilege, rather than an entitlement was mentioned by others and participants spoke about how attitudes of Italian society reinforced the view that facilities were seen as

benefits, rather than duly given entitlements. However, whilst recognising that Italian society lacked understanding about disability issues and was ignorant about required facilities, many women talked about how they thought others did not understand because they had not been exposed to living with a disabled person and so could not conceive what life was like for them.

"Because they don't have anyone at home...anyone in their family who isn't well and they don't understand" (Patrizia, group 2).

The lack of understanding because of the absence of exposure to the lives of disabled people was spoken about by many women, and all the women interviewed for a second time discussed how those in positions of power failed disabled people because of their insufficient contact with disabled people.

"the government doesn't do anything for disabled people!...there's nothing, very possibly because they are not capable of putting themselves into my shoes...they don't reduce taxes to help disabled people. In fact, it seems almost like...no, in my opinion, yes, they don't think about [disabled people] at all!" (Elisa, group 3).

This suggests that bureaucracy and government policy were perceived by the women as influencing society's attitudes towards disabled people. Whilst many of the women recognised the role the government had to play in managing issues and attitudes towards disabled people, there was clearly still a long way to go.

"...still today...unfortunately, people with disabilities are seen as people who want...mmm who beg for handouts, right! And who don't have any rights due to them...." (Cristina, group 3).

We discussed with the women who were interviewed for the second time, their thoughts about the future; whether they thought things needed to and would change for disabled people, and whether they felt that their being disabled mothers would impact on their children's attitude to disability. Elisa told us that change would need to be fought for and that change was needed. Patrizia told us that she hoped that because her children had grown up around a disabled person they would have a better insight.

"Yes, in my opinion they'll be more...having this experience at home...they understand the world of disabled people more" (Patrizia, group 2).

Although Elisa, Ottavia and Sonia had hopes for the future, they did not have much confidence that things would change. An example from Alessandra indicates that there is still some way to go regarding the future and changing attitudes. She told us about a family trip she had made to a holiday destination where the children were interested and curious about her being in a wheelchair.

"and there were some parents who would not let their children come near me because I'm sick! I mean, it's sad!...and the ignorant parents say 'leave her alone'! I mean, what harm could it do? It's not like I'm a leper! And I hope that their children grow up to be more intelligent than their parents! But unfortunately, with ignorant people like that around them, that'll be quite difficult!" (Alessandra, group 3).

As well women discussing the attitudes of general society towards disability, attitudes of doctors also arose as a sub-theme, in relation to decision making around motherhood.

7.6 Medical Influence and Decision-Making.

In terms of medical support around becoming a mother, for those women who already had a diagnosis when they decided to get pregnant, the advice from doctors varied. The role of doctors in the lives of my participants is particularly relevant, as a nationwide research survey found that Italians viewed the role of doctors with the highest regard of all medical professionals (Coulter & Magee, 2003). Furthermore, an Italian study which investigated decision making in people with MS (Giordano et al., 2008), found an overwhelming tendency towards a passive or at most collaborative role, suggesting the potential powerful influence of doctors' advice in this cultural context. Some women were advised against having children. One of these was Fiorella, who told us:

“the professor [her neurologist] told me that I would pay the consequences for the rest of my life and that my disease would progress drastically, I said that I didn’t care! I wanted to go ahead with it because I wanted to become a mother! Absolutely, I was...I was happy to have succeeded” (Fiorella, group 3).

Erica and Silvia were also advised by their doctors not to have children due to the potential for them to relapse. This was a huge shock to Silvia who had been married for four years and she and her husband had planned to have children together. Soon after, Silvia fell pregnant “not because I had wanted to, but I was pregnant just the same”. However, because of what she had been told by the doctor her pregnancy was not a relaxing one:

“I went through nine months of pregnancy with the fear that I might wake up one morning and not be able to walk anymore...” (Silvia, group 1).

This demonstrates the potential impact of the advice given by doctors, not just on whether or not to have children, but also on how women felt throughout their pregnancies. Although Silvia did not have a relapse post child birth, this was not the case for everyone. Alessandra had been told that she could relapse if she had a child, which did turn out to be the case and she relapsed and became a wheelchair user when her daughter was a young baby. However, despite the fact that she had been cautioned against having a child, Alessandra had decided to go ahead and have a child even though she knew the possible risks.

“because when we decided, when we felt ready to face a period like that, I mean, we decided to have a baby and that was it...I mean, we decided that despite the thousand problems we might have to face...but we decided to do it and it was okay! I knew that it would be tough, but I did it and it was all right!” (Alessandra, group 3).

These four women therefore showed that they prioritised becoming mothers over the medical cautions they had been given; which demonstrates the value of motherhood to them as women (see 5.3 ‘value & centrality of motherhood’). This is particularly striking given the reverent attitude towards doctors in this society.

Other women were not explicitly cautioned against having children, but were advised to have children as soon as possible, if this was what they were going to do. One of these was Rosa, who was twenty years of age when she was diagnosed and was told to have a child straight away if it were her intention to become a mother. So Rosa went ahead and became pregnant:

“without even being officially engaged, without even being married...well, you could say we rushed things a bit when it came to that...it was like jumping off a sky scraper!” (Rosa, group 1).

In contrast to Alessandra, who took on board medical advice, but made her decision independently of it, Rosa indicated that she felt pressured by her doctors:

“even if I became a mother at a young age, not because...perhaps not because I wanted to, but because they imp...mmm, no, not really imposed, I mean, because they said those things, they made me...I mean of course they let me decide...I mean, of course I could have decided not to become a mother...and no, I am happy to be a mother...” (Rosa).

Rosa’s hint of suggestion that her doctors tried to impose their views onto her, highlights the potential influence medical opinion can have on women with MS who want to have children. Although aware of the possible risks having children could have on their MS, the women in this study who knew their diagnosis placed the value of having children above that of their MS worsening, but many other women living with MS may have decided not to have children following their doctors’ advice.

For some of the other women in the study who had symptoms of MS but were undiagnosed when they became pregnant, their decision making would have been made more complex by medical advice. Julie had some symptoms of MS prior to the birth of her daughter, but had been diagnosed with a different condition. After her daughter’s birth and subsequent diagnosis of MS, the realisation of her condition hit her hard, and she told us she felt like her world had collapsed. However, she was thankful that she did not know she had MS when she became pregnant, as although she reported that she would

most likely still have gone ahead and had a child, she was not sure. Delia was also unaware that she had MS when she decided to become pregnant as she had been diagnosed with a different condition.

"I mean, really, I didn't pay it much attention, I didn't think it was something like multiple sclerosis. And...then when I ask--...I even asked my neurologist if there would be implications for having children and he said no...so I did it! But perhaps, if I'd have...I mean, I knew what I really had perhaps I wouldn't...perhaps I wouldn't have had a child! [laughs] Then they call--...they began to call it by its name when I was pregnant...and the relapse was really tough!...And so, at that point, they started calling it multiple sclerosis." (Delia, group 1).

The experiences of Julie and Delia highlight the value associated with having accurate information on which to base decision making around pregnancy, but the added complexity knowledge of the condition could bring to decision making. Other women had open and frank discussions with their neurologists about possible implications about having children, which was felt to be helpful. Sonia's neurologist, whilst supporting her decision to become a mother, took a rather blunt approach and informed her that her child might grow up with a 'handicapped mother'. Sonia had also previously seen a neurologist who did not have a positive attitude towards women with MS having children and indeed in pursuing other areas of their lives. She told us following her consultation with this doctor:

"...practically he wanted me to lock myself in my home and finish my life there with my disease! And I left and I said 'look, what you've said, that doesn't matter a bit to me!'...if I had done what he had told me, I wouldn't be where I am today, I

wouldn't be outside, I wouldn't have a daughter and all that, if I hadn't and so, no, no, women with multiple sclerosis can manage to be mothers, absolutely!" (Sonia, group 1).

The need for accurate information being available for women with MS was also highlighted by others who did not have symptoms of MS prior to becoming pregnant. For Maria, had she known of her condition and received pertinent information as to the possible outcomes of a pregnancy with MS, she may have been able to make a more informed decision.

"If I'd have known beforehand, knowing the life that awaited me, knowing that I wouldn't be well after I'd had them, I wouldn't have had them" (Maria, group 2).

Maria was one of the women who felt that her MS was 'winning the battle' (see 5.4 'maintaining control') and who spoke of her reticence about going out in a wheelchair. This indicates that Maria was concerned about the stigma for her children in having a mother who was disabled, and the stigma that she felt in being a disabled woman (see 5.6 'stigma & disclosure'). Maria expanded to explain that it was concern for her children's welfare, rather than her own, that she felt this way, although she expressed sadness at how she perceived she had not been able to be fully involved with her children.

"...I mean having my own children see me like this...no, it's sad, not being able to do certain things for my children and when they say, hey...there's this birthday, there's...let's got to a festival and I can't go...well, you don't know how I feel...I can't tell you [how I feel] [starts to cry]" (Maria).

The combination of her own fear of being stigmatised and the fear of stigma for her children, reinforced by barriers that precluded her from being fully involved in her children's lives had led to Maria questioning her decision making over becoming a mother.

For Cristina, not knowing her diagnosis was seen by her as an advantage, as she did not have to make a decision based on knowing that she had MS:

"if I'd have known [that I had MS], I don't know if I'd have had another child!...they took ten years to give me a diagnosis, anyway...it was bad, because you are there, stressed because you don't know what you have and why you have all these problems, however, you could say that out of the bad came some good in the fact that I had my youngest, who is truly...my joy!" (Cristina, group 3).

Both Maria and Cristina expressed doubts as to whether they would have made the same decisions around having children in part because of their perception of how they would manage the tasks of child rearing and whether they would have sufficient support. Even for those who did have their family around them to offer support, their MS still impacted on their decision-making around having children. Alessandra told us that, if she had the money to allow her to, she would love to have more children, but the fact that she knew that it would mean her family needed to provide more help to her also prevented her from having other child.

Of all the women who expressed doubts as to whether they would have made different decisions had they been aware of their diagnosis, what was striking is that the influencing factor was how they would manage to raise their children, rather than a personal concern for their health and well-being. For Alessandra, who knew she had MS when she decided

to have a child, but had a relapse soon after, and for Elisa, who had a relapse within a few days of the birth of her son, both questioned whether they would have had a relapse with or without being pregnant.

“But I have often wondered if it might have happened anyway, without [me having my child], I mean, I didn’t associate maternity with the relapse...anything could have happened, or nothing...in my opinion, even though I did get worse, I could have also gotten worse in other circumstances...” (Elisa, group 3).

The experiences of the participants in this study indicate the importance of women wanting to be as informed as possible with regard to maternity issues and MS. However, the enormity of the impact of physical barriers on disabling women in their role of mothers also needs to be taken into account. Whilst some women had relapses post child birth, leading to further impairment for them, it should not be forgotten that their ability to then be successful mothers was also heavily influenced by the barriers around them, not wholly by the level of their impairment.

7.7 Conclusions on Challenges and Support within Society.

“... if disability was normal to our institutions, it would then become normal to 90% of the population. If, instead, disability is seen the way it is, like something that shows you are different, well then, it’s something that affects everyone...if something wasn’t treated as something strange, unusual, then everyone else would think it was normal too. If disability became something normal, perhaps other people would slowly begin to consider it normal too...you wouldn’t notice the

person in a wheelchair anymore, even if she is young, because you're used to it..."

(Ottavia, group 2).

This comment from Ottavia embodies many of the issues raised with the superordinate theme of 'Challenges and support within society'. Seeing disability as being "different" exemplifies the ignorance from society as a whole, and from the government, which many women reported. As Sonia remarked:

"it is the government that represents our society and from an ethical and legislative point of view, the government should establish how a civilised society should behave!" (Sonia, group 1).

The lack of state concern for ensuring disabled people had their rights to equality met therefore perpetuated ignorant attitudes within society. This is shown in how women described the lack of accessible facilities and resources available to facilitate their independence, and the view that disabled facilities are seen as benefits rather than rights. However, many of the participants also discussed their own complacent attitude towards disability prior to realising the limitations that society placed on them as women with impairments, and discussed that unless you were living as a disabled person in society, it was difficult to appreciate the challenges society presented.

Regardless of their level of impairment, the women in this study identified a range of barriers which precluded them from full participation in their children's lives. These barriers were a variety of physical obstacles and architectural barriers, including inaccessible public transport and geographical environments. This forced many women into positions of dependency on others, or led to them not being able to participate in the activities with their children at all. Some women found strategies for managing these

issues, enabling them to maintain more independence or involvement in their children's activities. However, despite their stories of how barriers impacted on their ability to fully participate in their role as mothers, there was a lack of expectation that the state had a role to play in redressing this and challenging the barriers, and a lack of hope that this situation would change in the future.

The three analysis chapters have highlighted some interesting key superordinate and underlying sub-themes which give insight into the lived experience of disabled women in Italian society. In view of the existing literature on disability and parenting, which arises from countries other than Italy, and the socio-cultural context of Italy, which were discussed in the literature review, the following chapter will contextualise the themes from the analysis by considering my research findings in relation to the current discourse on disability and parenting.

Chapter 8 – Discussion:

8.1 Overview.

Within the limited academic discourse on disability and parenting, the voices of disabled mothers in Italy are mostly absent, and the general literature around disability continues to focus on a deficit based discourse, rather than recognising the socially constructed barriers that disabled people face in Italian society. The existing literature has recognised that further investigations are required in order to discover more about the experiences of disabled parents, for example the quality and level of assistance available to disabled women in their parenting role (Storr, 2007). My study gives an insight into the lack of formal publically funded assistance to support disabled parents, as well as the high level of informal care provided to disabled women in Italy by their family members. My study has been able to examine the experiences of mothers living with MS, and has demonstrated that the impact of this long-term condition can be multi-faceted and wide-ranging. These issues have been highlighted by listening to the voices of women who have multiple sclerosis, living with the phenomena of life as a disabled mother. The voices of the women have been represented in the findings through the use of interpretative phenomenological analysis, to exemplify lived experience. Specifically, the study set out to answer a series of questions, which were:

1. What factors have impacted on the women's roles as mothers since the onset of their MS?
2. Is the time of diagnosis relevant to the impact of MS on the women's experience of motherhood?

3. In what ways do wider influences in Italian society, such as the church and the legacy of a government led by Silvio Berlusconi, impact on the lived experiences of disabled women in Italian society?
4. How do external barriers, such as environmental, societal or attitudinal, impact on the women's experience of being disabled mothers?
5. In what ways does this empirical study on the experiences of Italian women with MS contribute to the wider understanding of issues around disability and motherhood?

This chapter will discuss the key elements from the findings of this study in relation to the first four research questions and will conclude by answering the fifth research question in suggesting ways in which the findings contribute to the wider discourse around disability and motherhood, and the chosen methodology. My research questions will be considered in turn.

8.2 What factors have impacted on the women's roles as mothers since the onset of their MS?

One of the factors that arose as impacting on the women's roles as mothers was how the women perceived their roles as mothers, and how they viewed the roles of family members in supporting them.

8.2.1 The Influences on the Gendered Role of Mother.

All of the mothers in my study highlighted the enormous value they assigned to their mothering role, which may be because of the huge emotional investment placed on

having children in Italian society (Dalla Zuanna, 2001). Whilst studies suggest that people with long-term conditions redefine their life priorities (Reynolds & Prior, 2003), the findings of my study give reason to suggest that the positive associations of motherhood also impacted on the significance and priority my participants gave to their mothering role.

Like some of the women in Payne and McPherson's study (2010) of mothers with MS, some of the women in my study alluded to their notion of an ideal mother and how they viewed they fell short of this archetype. This was evident in the number of women who spoke about making comparisons, either with non-disabled mothers, or with themselves prior to being diagnosed with MS. This was in relation to how they viewed differences in the manner in which they parented their children, or how they perceived their children compared them to other mothers. The tendency to compare and for some, to feel different, indicates that the women in my study were comparing themselves against a personification of an ideal mother, which would be influenced by their cultural environment. Indeed there was evidence that the motherhood role was culturally influenced in terms of gendered role expectations and a fundamental aspect of my study was the cultural regulation of gender specific roles, when considering adjusting to changing responsibilities and tasks. This is in the context of a country that continues to have a significant gender division of labour, both in relation to employment, and within the family home. Whilst many of my study participants delegated tasks to their husbands, both in accompanying children to activities and taking responsibility for household tasks, some expressed regret at having to do this. This was not only because the women felt a sense of loss at missing out on activities with their children, but also because of the challenge this presented to stereotypical gender roles. Therefore for some women,

delegating tasks to their husbands challenged their own culturally defined roles as mothers and influenced how they felt they had maintained this role. Although the longstanding assumption that husbands should not routinely participate in household tasks is beginning to shift, this expectation persists in Italy (Saraceno, 2004; De Rose et al., 2008; Craig & Mullan, 2010) and there continues to be a reluctance of men to participate in child care tasks (De Rose et al., 2008). This may then also contribute to the women's sense of loss of the culturally entrenched expected role as a wife and mother. As Zontini states "Cultural norms and values influence how families operate and how care should be arranged within and across households" (2006:342). Therefore when care responsibilities change, these conflict with cultural norms and traditionally defined expectations of family roles.

Gender specific roles were also influential in terms of how women thought about the roles of their children in the future. Alessandra made reference to how she felt fortunate to have a daughter, rather than a son, as she was foreseeing needing help from her daughter in the future. Leona also spoke of her worry about becoming a burden to her son and Maria told us how she wished her daughter would assist her more, rather than her son. In Maria's case, this may also relate to the ages of her children, as well as their gender. For the women in my study who delegated tasks to their husbands to carry out with their children, there was an expressed concern about challenging the "traditional sexual division of labour" (Thomas, 1997:639). For example Maria told us that she "suffered" because her husband took over many household tasks. Despite this, she also told us that she saw it as an obvious solution that her husband took her son out on his bike, as she was not able to do this. The conflict between ensuring her child's needs were met, fulfilling her role as an ideal mother, and her culturally entrenched gender defined

roles of herself and her husband caused her distress. Maria was not alone in this conflict of interest and other women who delegated stereotypical mothering tasks to their husbands also felt they had lost part of their role. For some this put their role into the background, unlike the women in Thomas' (1997) study, who continued to be the main carers for their children and other family members. This caused conflict for many of my participants because of the stereotypical image of Italian mothers, who are renowned for continuing to fully care for their children, well into when their offspring reach adult age, whilst they remain living in the family home (Saraceno, 2004).

There are other influences in Italian society which reinforce the stereotypically defined role of mothers. For example, availability of part-time work is sparse, leading to women having to choose between not working and working full-time (De Rose et al., 2008). This means that women with children often stay at home as full time mothers, thereby reinforcing their gender stereotyped role of being the homemaker, with their husbands subsequently adopting the gender defined 'breadwinner' role. A number of my study participants had challenged this stereotypical image and had been in work until the impact of their symptoms, or the environmental barriers in the workplace, had put them in a position of having to finish working. However, there was also an indication from some of the women in my study that there was an expectation that a woman's natural place was to be at home and a couple of the women made specific reference to how their husbands had encouraged them to prioritise their roles as mothers, again reflecting the stereotypical gender division of labour and life roles in Italian society. Alongside this, many women themselves spoke of how they had prioritised motherhood above all their other roles, which reflects the value of a nuclear family construction in this cultural environment.

Although it was not explicitly brought out by many of the women in my study, the gendered division of roles may implicitly be influenced by the Catholic Church. As Fiorella stated “Jesus Christ made us have children in two, so there needs to be a mother and a father...” As the only woman in my study who was not married, Fiorella reflects the cultural expectation of two parents to raise a child and the underlying religious influence on this. Her reference to relying on one’s husband for support is influenced by cultural expectations that “family solidarity remains the main, and sometimes the only, resource in case of need, either financial or of care” (Saraceno & Terracina, 2005:182). This aspect will now be further explored in relation to the role of family and friendships.

8.2.2 Relationships and the Role of Family and Friends.

Another factor that arose with regard to the women maintaining their role as mothers was around their views on any support they required. In a country where welfare provision for vulnerable members of society is scarce, there continues to be a strong reliance on an extended family unit (Saraceno, 2004) and the constitution of a robust family continues to represent an “ingrained anthropological feature” (Dalla Zuanna, 2001:139) in Italy. This was reflected in the findings of my study, in which all the women spoke about the support they received from others who were beyond their nuclear family unit, with many women relying on their extended family members to provide them with support.

However, what is necessary to consider at this point, is that when studies address issues of ‘support’ in the context of Italian culture, they frequently fail to define how support is conceptualised (Tomassini et al, 2007). One study examining support in Italy which does

clarify its definition of support defines 'Informal support' as being that which is provided by family, friends and community networks; and 'Formal support' as that which comes from public social services (Tomassini et al., 2007). Such studies recognise the level of intergenerational 'informal support' that ordinarily exists within Italian society, regardless of disability. It could therefore be proposed that for those women who received support from their parents and extended family members, (which comprised a significant number of the women in the study) that support would have been offered to them in any event as in Italian culture, regular and frequent contact amongst family members is commonplace (Rizzi & Kertzer, 2010). This may explain why some of my participants who had the least level of impairment, saw the assistance they received as 'normal family help', as it did not differ from that which would ordinarily be given between family members. However, some of the more impaired women, whilst acknowledging the help that family gave them was necessary, expressed some regret and stifling of their mothering roles at the level of help their families gave them.

There was therefore a distinction between support that was ordinarily offered by families, and that which went above and beyond that usually expected. For the less impaired women, the support they received from family members was not particularly different to that which their peers would have had; and they showed more reluctance to ask for additional help and exhibited determination in continuing to battle with their disease and gained strength from maintaining their role in caring for their children. For those who required more physical hands on support with their children and their own care, they had to make more adjustments to how they maintained their mothering role with their children and shared this more with family members, for example by delegating childcare tasks to their husbands or wider family members. So even if the women were

not physically able to participate in tasks themselves, they compromised and modified their mothering role by using support from others to carry out activities with their children on their behalf. However, a few women struggled to regulate the level of family support, which impacted on them feeling that they had not always been able to entirely fulfil their desired mothering role.

This increased level of support offered between family members accords with Zontini's (2006) contention that families are resilient units that adapt to different circumstances. This resonates with the findings of my study, in which family members stepped in to help spontaneously, naturally adjusting to the circumstances of the women and automatically adapting the type and level of assistance given. This may also have been aided by the proximity of many of my participants and their families, as a major factor that transpired was the reliance on family support and the nearness of habitation between many of the women and their parents, which is a common occurrence in Italy (Dalla Zuanna 2004; Rizzi & Kertzer, 2010; Zontini, 2006).

The construction and maintenance of the archetypal Italian family which constitutes "the fundamental nucleus of society" (Crowhurst & Bertone, 2012:413) is somewhat challenged by the presence of a disabled woman within the family group, in that the dynamics of care responsibilities shift. The existing literature on inter-generational support in Italy largely focuses on the care of children and elderly people. There is an absence of literature that considers intergenerational care issues for disabled people, particularly for those who are almost exclusively expected to take responsibility for care of children and elderly parents, that is, women (De Rose et al., 2008). For some of the women in my study, their ability to provide hands on care for their children and their

elderly parents declined, not least for those who had fatigue, but also for those who had more significant mobility impairments. Putting to one side for now the fact that those with mobility impairments were hindered in their ability to provide upward and downward care (Rizzi & Kertzer, 2010) for elderly relatives and their children, due to the numerous environmental barriers they faced; managing the symptoms of their MS also challenged the caring responsibilities for a number of women in my study. Some women struggled to ask for and receive support from their elderly parents, but had no alternative person on which to rely. In this way, there was a reversal of roles, with some of my study participants needing support from their parents, which they ordinarily would have provided to them. Delia, Fiorella and Francesca made specific reference to their regret at this necessary role reversal. This may have contributed to why a number of my participants spoke about living in the moment and not thinking about the future, not only mindful of the potential of their disease to worsen, but also aware of the culturally expected contribution they should make in caring for their own parents and children.

Whilst some of my participants appeared to struggle to delegate tasks to family members, others appeared to have a more reconciled attitude and as such could be said to have adjusted more to their changing roles. Delegation of tasks and acceptance of help from family members may also have been aided by the non-judgemental attitude of many of the families towards the women having children. However, there were also situations for two women in which one of their parents had withdrawn completely, reflecting the failure of some families to adapt to a changed situation, perhaps because of a lack of understanding, or the implicit stigma attached to association with a disabled person. The women who spoke about the withdrawal of family members simply asserted the actualities of this situation, rather than labouring on the detachment of these

relationships. However, an interesting point arose with regards to this. Although the two women mentioned above had lost contact with a parent, this was on account of difficulties adapting to MS in general, not due to their decision making around becoming a mother. A couple of the women spoke of how their parents were concerned for their well-being when they decided to become pregnant, but there was no indication from any of the women in my study that they faced any disapproval from their parents in becoming mothers. This is in contrast to the evidence in some studies in the existing literature, such as Thomas' study (1997) in which some of the women were not supported in becoming mothers by their family members. For the participants in my study who spoke of how their family members were concerned for their well-being if they had children; there was no evidence that families were questioning how the women would manage the tasks of mothering, nor the role that they might be required to take in assisting.

Indeed for the women who knew about their MS prior to having children, many spoke of how their decision making was linked to the knowledge of the availability of family support. There is a positive association in Italy around women's choices to have children and the existence of child care from grandparents anyway (Rizzi & Kertzer, 2010).

Therefore the confidence gained from awareness of the availability of support from family members may relate just as much to normal familial expectations, as to concern about the needs of my participants because of their MS. That is, knowing that they had a close family unit around them to provide support would give the women more confidence to have a child in any event, irrespective of the MS. Knowledge and assurance of inter-familial support for Italian women with MS around decision making on becoming pregnant needs further investigation, as other studies have not recognised the potential influence of this factor on choice making around pregnancy for women with MS (see for

example Prunty et al., 2008b). With a limited number of qualitative studies available that look at factors affecting decision making around childbearing for women with MS, the tendency has been to approach this from a medical perspective (see for example Smeltzer, 1994)

What was also evident in my study was that, similarly to Zontini's (2006) study participants, there was variation in how families were described, with many women referring to their 'family' to depict their husband, children and their husband's relatives; as well as their 'family' of origin, which represented their own parents, siblings and extended family members. Ottavia and Cristina had both migrated to the north of Italy when they married, leaving their family of origin behind in the south of the country. Both Cristina and Rosa described their feelings of having to manage 'on their own', as their family of origin did not live near them; and Rosa told us about the reassurance and support she continued to get from her family when she returned 'home' to visit. Again this demonstrates the value of family support and relationships within Italian society and how influential these factors were in ensuring the women maintained their role as mothers.

A study by Starks et al (2010) found that in couples living with one partner with MS, there was evidence of a variety of attitudes and behaviours that either helped or hindered their ability to work together to react to the challenges MS presented in their lives. Similarly, for the participants in my study, some had negotiated the symptoms of their MS to enable them to get on with their lives and adapt to changed life roles, working "in sync" (Starks et al., 2010). Starks et al (2010) found that significant factors for the "out of sync" couples were when there was a loss of role, identity and self-worth. For the women in

my study, those who spoke about their feelings of loss were less adjusted to their changing roles and self-identity, which could lead to lower self-worth. Considering that the women who had to make more changes to their role were the women who were more impaired, as physical barriers precluded them from fully participating in their children's lives, it could be assumed that these were the women who spoke more about loss. However, this was not the case and the women who spoke of loss were the women from the middle group (who were the women who had a degree of physical impairment which regularly impacted on their everyday function), suggesting they were in the process of adapting their roles as their condition progressed. These women felt they had missed out on some aspects and were different mothers to how they had perceived they would be, or had been previously. Part of the influence on perceptions of loss was related to how some of my participants had lost friendships, either because friends had distanced themselves, or because the women no longer felt understood and potentially valued by former friends. A number of women had lost highly regarded friendships when they had surrendered their paid working roles, something which has also been reported by other studies (Reynolds & Prior, 2003). For some of these women, they therefore sought out different friendships, to refresh their identity in different social circles. Three women made specific reference to the value of the companionship they had gained at the MS centre, which perhaps reflects the accepting relationships gained between those with a shared stigma (Goffman, 1963). The lack of understanding in friendships was not an issue for companionships formed at the MS centre, as the people there were all living with MS and had a shared knowledge of functioning as a disabled person in society. Although empirical studies have considered loss of friendships in the context of family social relationships (see for example Bowen et al., 2011), no empirical studies have specifically

considered friendships for mothers with MS. Future studies in this area would assist with identifying the influence of friendships on the mothering role.

Many women spoke of how they had encouraged their children to help with household tasks, or that their children had spontaneously assisted. This is interesting as in Italian families it is the usual perception that even adult children living at home are not expected to participate in household responsibilities (Saraceno, 2004). My participant's children were not only showing maturity and independence in dealing with their own needs, but were also assisting their mothers with managing their symptoms, for example by encouraging their mothers to rest to preserve energy, or fetching and carrying things for them. However, some studies argue that the increased role of children in providing practical support to their parents with MS can have mixed reactions, from the children feeling proud, to being stressed (Turpin et al., 2008). For the participants in my study, the context of their children assisting them was within a milieu related to facilitating their children's independence and autonomy, although for some this was precipitated by the knowledge of the unpredictable nature of their disease. Within the UK, there is a discourse around the plight of "young carers" who assist their disabled parents with everyday tasks, which could be argued is largely on account of inadequate provision of appropriate formal support being available. Concern about overbearing their children with care responsibilities was not raised by any of my participants, which may reflect the embedded expectation of all the family pulling together in times of need, or that the subject of child carers remains a yet unexplored topic in Italian society. Future studies looking at the role of children providing support to disabled parents in Italy would highlight this issue further.

In addition to discussing how their children helped out with practical tasks, my participants also spoke of how, when aware of the impact of their mother's MS symptoms, their children adapted their behaviour or expectations of their mother's ability to participate in activities with them. This substantiates the finds of Thomas' (1997) study, about the tendency of children to adapt their behaviour according to their mother's impairment. With the responsibility of household chores falling almost exclusively to women in Italian society (De Rose et al., 2008), the participants in my study challenged this gender division of labour within the home and the ways in which their children adapted their roles and expectations assisted my participants in successfully maintaining their roles as mothers.

Provision of informal support for my participants therefore raised a number of issues to do with culturally expected family roles and gender specific responsibilities. To one extent or another, all my study participants were supported by their family members in their mothering role. However, this was not always beyond the normal expectations of intergenerational support, given that assistance among family members is commonplace in Italy regardless of the presence of disability.

8.3 Is the time of diagnosis relevant to the impact of MS on the women's experience of motherhood?

My second research question concerned whether the timing of the women's diagnosis was relevant to their experiences of motherhood. One area in which this became manifest was in relation to communication.

8.3.1 Communication & Adjustment.

A significant issue raised in my study was the level of communication between the women and their families, in contributing to whether they were working 'in sync' as a family unit, and in relation to adjusting to the presence of MS in their family life. For the women who were less impaired, there was more likely to be a tendency to deny the impact of their symptoms, or to conceal their symptoms and sometimes fail to acknowledge their diagnosis at all. However, for the women who were more impaired, their ability to deny the impact of their symptoms was more difficult, due to their more pronounced level of physical impairment. These women, whilst sometimes expressing sadness at the loss of aspects of their mothering role, had a more stoical attitude towards dealing with their MS, being more likely to attribute the source of their disability to external factors, rather than internalising their impairments as being the focus of their disability. For some of the least impaired participants, adjustment to MS was more complex, with women battling to manage the symptoms of their MS and trying to maintain the status quo in their lives "As a person she [her daughter] considers me normal" (Julie, group 2). At some point my participants claimed their identity as disabled women (Rousso, 2013); shifting from their pre-existing identity before they had been diagnosed with MS. This redefined identity may relate not only to the level of impairment of MS, but also to the length of time my participants had been living with MS, the speed of progression and the type of MS they had. These aspects were not specifically considered within my study, but many other studies have investigated adjustment to disability and MS (Irvine et al., 2009), with some suggesting that reliance on social support leads to better adaptation to MS (Wineman, 1990). Other studies have argued that children adjust better to their parent's MS if their parent has a positive approach to their condition (De Judicibus & McCabe, 2004). As well as women gaining confidence in their

mothering role because family members were happy to assist them, this support also facilitated their children's adjustment to having MS in their lives, which has been reported in other studies (Bogosian et al., 2011).

Another significant factor in my study in relation to redefining one's role was the timing of diagnosis and onset of symptoms, not only with regards to whether the women were already mothers at diagnosis, but also the ages of the women's children when they became impaired because of their MS symptoms. For the women who already knew their diagnosis when they decided to have children, or who became more physically impaired when their children were younger, there was an openness in communication and the women developed a persona of a mother living with MS from when their children were very young. Many of the women who knew and were open about their diagnosis when their children were young, also spoke of how their children assisted them naturally and spontaneously, suggesting that timing of diagnosis is relevant to a child's ability to offer unprompted support to their mother. This engendered a natural acquiescence of MS in the lives of these families. In contrast for the women whose children were older when they became more physically impaired, there was more difficulty accepting MS into their lives. This led to some women, such as Cristina, Maria, Fiorella, Delia and Patrizia, having difficulties communicating with their children about their MS and enabling an understanding from their children as to how their MS impacted on them as mothers. However, these women attributed some of this lack of communication and reluctance to participate in household tasks, to the ages of their children. An interesting example is that of Elisa, whose son was eleven when we interviewed her, so perhaps had not yet entered the realm of more confrontational teenage reluctance to assist with home tasks. Elisa spoke of how her son naturally stepped in to assist her and did not speak of difficulties

getting him to assist with day to day household tasks that other women with older children did. A future study to investigate whether for the women with younger children who spoke of the ease of communication and acceptance of MS by their children, this situation changed as their children became teenagers, would offer a greater insight into this issue.

8.3.2 The Significance of Motherhood.

Another area in which the timing of the women's diagnosis was relevant was in respect to the value of motherhood. A number of women who were aware of their diagnosis prior to having children had been cautioned against embarking on motherhood by their doctors, or had been encouraged to go ahead with this sooner rather than later. What is particularly significant is that among the women who were told that having children could lead to a relapse (although more recent research somewhat refutes this link), they valued becoming a mother over the potential of their disease worsening. Even for Silvia, who told us she spent the whole of her pregnancy fearing a relapse, the value of becoming a mother outweighed her qualms. In terms of the relevance of the timing of diagnosis, the women who knew their diagnosis prior to becoming pregnant showed strength in making the decision to be mothers, despite sometimes discouraging advice from medical professionals, who are highly valued in Italian culture (Coulter & Magee, 2003). Some women who knew their diagnosis also spoke of their family's concern for their well-being in pregnancy and following childbirth, but had made the decision to go ahead anyway. In contrast, for women who did not know their diagnosis, some expressed that they may have had doubts about having children had they known they had MS, though all still highly valued their role as a mother and all but one of the women who talked about how their children gave them the strength to get up each morning and to keep going, they had

not known their diagnosis when they became pregnant. This suggests that the value and joy of motherhood suppressed the prominence of MS in their lives, with the women instead focused their energies on their children and gained strength from this. For the women who knew their diagnosis when they decided to have children, more spoke of the pride they felt and how they thought others recognised their achievement in having children. This perhaps relates to the inner strength women had shown in making this decision despite unenthusiastic support from those around them, particularly doctors, but it also may link to how the women showed their strength against the power of MS. More of the women who spoke about their anger at having MS and their loss of control in their lives, were women who did not know their diagnosis when they became pregnant. This would suggest that the women who did know their diagnosis had more time to prepare for motherhood and the potential need to share and delegate roles, and therefore were able to maintain more control over elements like this in their mothering role. My study offers a unique contribution to the literature, by comparing the timing of diagnosis in relation to how women felt about their roles as mothers with MS. This was particularly so with regard to women who spoke of feelings of loss, as although studies have considered issues of loss for people with MS (Bowen et al., 2011; Guerra, 2013), no empirical research has explored these issues for women with MS in relation to the timing of diagnosis.

At the time my research was undertaken, the Italian political discourse was “dominated by the overwhelming personality of Silvio Berlusconi” (Ruggiero, 2012:318). Despite leading the Italian government for four terms of office, suggesting his popularity with the voting public, within the English speaking media, Berlusconi’s leadership was marred by personal scandals, including his womanising behaviour. However, these factors were

seemingly not significant in leading to Berlusconi's forced resignation from government in 2011, which was instead attributed to the international economic crisis (Ruggiero, 2012) and a general underperformance of the government (Marangoni, 2011). With these factors in mind, it was felt appropriate to investigate how my participants viewed the legacy of Berlusconi's leadership and the general role of the government in their lives.

8.4 In what ways do wider influences in Italian society, such as the church and the legacy of a government led by Silvio Berlusconi, impact on the lived experiences of disabled women in Italian society?

In addressing this research question, it was necessary to consider the wider socio-political agenda in Italian society. As indicated earlier, the welfare state in Italy is less well developed than that in other European countries although it has been suggested that the Italian welfare system is not lacking capital, but directs its resources mainly to the elderly, financing pensions, rather than distributing money to fund public services, which would have a broader remit of providing assistance (Dalla Zuanna, 2001). This was mirrored in my study, where a number of the participants substantiated that the government did little to support them financially. My participants spoke about how, other than a disability pension and some minor tax deductions, they had no financial support from the government. These financial issues were evident in different ways, for example some women in my study spoke of not being able to access disabled parking bays and badges, necessitating them paying high costs for city centre parking; or in Sonia's case, for recurrent parking fines incurred by her need to park near her home. The vast majority of women in my study also either drove themselves or relied on other people to drive them,

rather than use the relatively cheap systems of public transport, as this was inaccessible to them. A couple of the women had also had their free hospital transport withdrawn, due to budget cuts.

Social policy generally in Italy has financial and practical disincentives for women to work and therefore forces them into a position of financial reliance on their husbands (Saraceno & Terracina, 2005). Whilst some of the women in my study had worked, only two remained in paid employment at the time of my study, both of whom were women with the least level of impairment. A number of women had given up work because of their MS, which meant they became financially dependent on their husbands and families, or faced financial hardship. Whilst issues around employment of people with MS in Italy have been addressed in other studies (see for example Uccelli et al., 2009), a combination of social policy factors prevented my participants from continuing in the work place. The general disincentives for women to work combined with the environmental barriers in the workplace described by my participants, predetermined their chances of working and showed that they had much to challenge if they wished to remain financially independent. Their gender and their impairments both negatively impacted on their ability to work, and these equality issues are still insufficiently addressed by government policy (Naldini & Saraceno, 2008).

Issues around equality for women in Italy have been marred by the governance of Silvio Berlusconi, which has left a legacy of unhelpful stereotypical images of women (Pianigiani, 2011), whilst at the same time there is an underlying lack of political agenda

to address issues around equality for disabled people. Italy has been slow to take on board initiatives to improve equality and the rights of disabled people (Bell, 2008; Boeri & Ferrera, 2001; Saraceno & Terracina, 2005) and there remains a distinct lack of awareness of disabled people throughout the whole system of social quality markers in Italy.

Saraceno and Terracina (2005) suggest with regards to social protection, Italy has “little positive actions to support access and efficacy” (pp.181). The lack of optimism for change in the future was evident in the accounts of women in my study, who had little hope of significant increase in support available to them, other than from within their own families. This change was related to those women who saw positive factors that their children would grow up with an increased understanding of disability, and would therefore initiate a shift in attitudes towards disability for future generations.

It is argued that there is a general lack of trust in public services in Italy (Dalla Zuanna, 2001). My study participants did not indicate that they lacked trust in the public sector, but that they had no expectations that it would provide them with appropriate services “really, you have to go private...that’s the way it is...” (Leona). For the women in my study there was no belief that the political agenda would address their needs as disabled people. A number of my participants felt that no one in central government had a lived understanding of disability, and as a result they felt overlooked and that issues around disability equality would remain unaddressed. This links to how many participants spoke of how they were ignorant to disability issues before they became disabled themselves and only by living the lives they did as disabled people did they become aware of the barriers society presented to them. As there is a lack of disability rights within the Italian political agenda and moreover an absence of disability issues being raised in the media, the issues around equality for disabled people remain hidden. In the aftermath of the

Berlusconi government, the political instability in Italy and the global economic crisis, the current political agenda has “economic crisis-driven priorities” (Crowhurst & Bertone, 2012:416) and issues of marginalised groups, such as women and disabled people, will not be top priority.

Due to its prominence in Italian culture, there is potential for the church to play a positive role in promoting issues of equality for disabled people and women in society. The church’s influence was therefore considered one of the possible socio-cultural factors to explore in my study, particularly due to the role the church has in influencing society’s attitudes (Garelli, 2007) and thereby potentially influencing the political agenda (Naldini & Saraceno, 2008). However, explicit questions regarding the church’s influence were not asked in the first interviews, and none of my participants specifically made reference to how the church impacted on their day to day lives, although it may be that the indoctrination of the church is so deeply ingrained in the culture of Italy, that any conscious awareness of its impact was hidden. The term used by Fiorella when speaking about how God made men and women in order that they had children alludes to this. To explore this issue further, in the second interviews, we specifically asked the women whether they thought the church had a role to play in dictating how society responded to disabled people. Although almost all the women attested to be believers, only one woman (Ottavia) said that having MS had brought her closer to her faith, specifying that it was her faith, not the church, to which she had become closer. None of the women indicated that the church had any positive role to play in supporting them, or in challenging the inequalities they faced as disabled people.

Within the feminist and disability literature, it has been suggested that disabled women are “doubly disadvantaged” on account of them being both women and disabled. Although there have been arguments to suggest that this portrayal is unhelpful, as it further reinforces the stereotypical images of disabled women (Morris, 1992; Morris, 1998). For women in Italy, this double oppression is in fact a reality, in terms of the socio-political agenda in this country. As has been shown, the government has not reacted to address the rights of my participants as disabled people, and they are further precluded from full involvement in society because of the barriers they face. Additionally the lack of resources, both practical and financial, have continued to prevent my participants in being fully included in society, which reinforced the “difference” and the stigma attached to being a disabled person. Thereby a lack of political action from the government in addressing these issues supported this situation as being acceptable, and proliferated the stigma attached to being a disabled person in this cultural setting. As women living in this society, it is therefore perhaps not surprising that my participants had little expectation that the government would support them in overcoming these barriers. Analogous to other studies, my study substantiates the lack of funded support to meet the requirements of disabled mothers (Storr, 2007) and the environmental barriers which greatly contributed to preventing women from full social inclusion in the lives of their children. The following sections will explore such barriers further. At the same time in recognising from the above discussion that the government has a key role to play in addressing these issues, further aspects of the state’s role will also be raised in the following discussion.

8.5 How do external barriers, such as environmental, societal or attitudinal, impact on the women's experience of being a disabled mother?

The following sections will discuss how other barriers impacted on the experiences of my participants, in addition to the socio-political barriers already described. This involved physical or environmental barriers, but also included the attitudes of others, which had a consequent influence on wider societal barriers. In relation to this, the attitudes of the women with regard to the availability of external formal support is relevant to consider, as a lack of facilitative support could potentially contribute to societal and attitudinal barriers to their full participation as a mother.

8.5.1 Expectations and Delivery of Formal Support.

In Italy there is marked variation in funding and delivery of welfare services from region to region (Bettio & Plantenga, 2004; Natali, 2006), and a general underdevelopment of welfare services in Italy compared to other EU countries (Natali, 2006). It is perhaps of little surprise then that my participants relied on family support, which resonates with the contention that in Italy people in need of support have to rely on a more family based model of care (Miller, 2004). As my analysis has demonstrated within the superordinate theme of 'Relationships with others', intergenerational support, strong relationships between parents and adult children and subsequent geographical residential proximity, continue to exemplify the strength and resilience of Italian families (Zontini, 2006), which supplements weak statutory provision. As well as a tendency to rely on family support because of a lack of alternative provision, there are also cultural expectations from within the family that women will provide care and support to other family members in time of need (Bettio et al., 2006; Natali, 2006; Naldini & Saraceno, 2008). It is therefore to be

expected that the women in my study gained support from family members, as evidenced in my analysis, but it is also relevant to explore what formal support was available for my participants and their views on this.

In exploring what formal assistance the women in my study were able to avail themselves of, what was evident was the lack of expectation as to what they were entitled to receive and what their rights as disabled people were, which may in part be due to the variation in Italy of access to basic items and rights (Saraceno & Terracina, 2005). Some of the participants in Thomas' study (1997) had not sought hands on assistance as they did not think they were entitled to it, or they did not have the information about what services were available. Similarly, when questioned as to whether there was any area of support they would like more assistance with, the women in my study referred only to financial support, or additional support from therapists, and did not perceive that any practical support services were available to them, with only two women receiving any state funded hands on support. One of these women lived just outside the geographical region my study was based in, substantiating the contention of regional variation in support services (Coulter & Magee, 2003; Bettio et al., 2006).

The other woman who received hands on support from the state was Fiorella, who was one of the most physically impaired women in my study. She had asked for more help in assisting her in managing her daughter's needs, though she did not receive the extra assistance she asked for, as the social workers had failed to return her phone calls to respond to her request for help. So for the women in my study, it was not necessarily that they were not aware of what services were available, but that their lack of expectation was justified, and reflected the lack of service provision that existed. However, it is also

important to remember that some women did not want, or indeed did not need, formal assistance in their mothering role (Thomas, 1997).

It is argued that in Italy there is little incentive for the state to address issues of the lack of welfare assistance as “Families tend to solve their tensions by themselves; therefore, institutions are not particularly pressed to intervene” (De Rose et al., 2008:691).

However, it has also been contended that it is the lack of alternative provision, rather than the strength of family ties, that leads to people relying on family members for assistance (Saraceno & Terracina, 2005). For Fiorella, the one woman who was not living with her husband and whose family network consisted of an elderly mother and an estranged sister, the state was not able to fill the gaps in support that her family might ordinarily have assumed. De Rose et al (2008) suggest that, since the second half of the 1980's, the Italian government has concerned itself with four main objectives concerning family policy, one of which is increased social services support to children and elderly people. Although most of my study participants relied on their families for support, consideration by the government also needs to be given to recognising the need and providing formal support for disabled people of all ages, not just children and the elderly. This would enable a greater degree of choice for disabled people in deciding how support is provided. This would further empower disabled people around the assistance they require, by giving them an option of gaining support from state resources, rather than having no alternative but to rely on their family for assistance. If the level of state support was more robust, it would also lessen the burden of culturally defined care responsibilities that fall to all women to provide support to relatives who needed help. In other countries, like the UK, although availability of support is subject to eligibility criteria, the existence of formal state support is at least indicative of the political responsibility to

facilitate disabled people's participation in society. Such accountability by the Italian government was not evident within my study findings.

In the second interviews, when questioned directly about the role of the state in provision for disabled people, all five of these participants disparaged the lack of state provision generally for disabled people, which supports evidence that there is high criticism of public social policies when welfare is deficient (Saraceno & Terracina, 2005). However although my participants were critical of the lack of consideration by the state for their welfare, as there was a poverty of resources available to them; they did not instantaneously consider this to be a socio-political issue, as political responsibility for support was not raised in the first interviews. Indeed Saraceno and Terracina (2005) highlight a socio-political paradox where government policy increasingly infiltrates public domains, but public interest in politics decreases. They argue that this could indicate a measure of empowerment, with grass roots demonstrations indicating and influencing public opinion on social issues, rather than trying to effect change from within the usual political arenas. However, they also suggest a contrary view that moves towards expressing oneself outside the political sphere has stemmed from a widespread "feeling of powerlessness: there is no influence one can exert; the dominant groups are always the same; citizens have no power and they better not waste their time" (2005:184). This would accord with the responses of my participants who expressed more of a resigned acceptance that the situation was unchangeable. Whether this feeling of powerlessness is more amplified for disabled women rather than disabled men would give an interesting insight into perceptions of disability and empowerment within this socio-cultural context.

8.5.2 The Role of Professionals.

Within the limited literature on disabled parenting, one issue that is raised is the pejorative role of professionals, both in judging parental competence and in allocating services, which are further societal barriers to consider. Much of the literature discusses how disabled parents avoid contact with professionals for fear of having their children taken away from them; or because of fear of facing reprisal due to the increased role in assisting with care and household duties their children had, thereby incurring the label of 'child carer'. The participants in my study made no reference to fear of judgmental professionals monitoring their mothering role, most likely because there was a lack of professional involvement in their lives as mothers. There was no indication from my participants that involving their children in household and care tasks led to them being anything other than helpful and responsible family members. The discourse around children helping was in relation to increasing their independence and autonomy, rather than the women being fearful that their children's role would be construed as being a 'child carer'. This may also relate to the lack of professional interest in the potential of these children being 'child carers'. Reference to negative professional involvement was made only by one woman, who expressed some resentment that a professional was being sent to visit her to check her eligibility for a wheelchair.

Whilst there were some positives to the lack of professional involvement in the lives of most of the women in my study, this also meant that professional support in tackling the environmental barriers was absent, failing to support women in overcoming the discrimination caused by a lack of equality of access. So whilst the women in my study were not subject to the pejorative role of professionals in assessing their parental competence, to which other studies on disabled parenting attest, they also did not

benefit from the barriers they faced being exposed and challenged in the wider professional discourse. My participants therefore were isolated in confronting barriers, rather than having the collective support of professionals who have a role in facilitating equality of access for disabled people and addressing discrimination through provoking social political change.

The other area in which professional attitudes was referenced was with regards to decision making around becoming a mother, with decisions on motherhood being defined as “the choice to forego, start or enlarge a family” (Prunty et al., 2008b:108). Though the women in my study were already mothers and therefore could not forego having children, comparison of the accounts between those who knew and who did not know their diagnosis when having children is relevant to consider, as some women may have foregone the choice to become mothers, had they known their diagnosis. This has been specially explored earlier, in the discussion around my second question on timing of diagnosis. However, in view of the high regard given to doctors in Italian society (Coulter & Magee, 2003), it is also relevant to consider further here, in relation to how attitudes from doctors have the potential to impact on societal barriers for disabled women. Historically, women with MS have been discouraged from becoming mothers (Payne & McPherson, 2010) and although more recent medical literature sets aside some of the previous negative links between maternity and MS, there continues to be concern from women around the potential impact of MS on pregnancy (Smeltzer, 2008). Within my study there was variation in the approaches of professionals regarding the women becoming mothers, with some women being told to have children as soon as possible if that was their wish, and others being advised against it. Therefore, for the women in my study who knew their diagnosis prior to having children they were drawn into a “risk

discourse” (Thomas, 1997:633) around their decision to become a mother. Although it could be contended that pregnancy and birth presents risks to any woman (Payne & McPherson, 2010), earlier medical studies suggest that the perceived risks are more significant for women with MS (due to the potential for a relapse), and this association continues to be pervasive. Indeed in the literature that considers MS and maternity, the most prolific discourse is around risk (Twork et al., 2007) and there are a lack of studies that suggest positive strategies for women with MS (Payne & McPherson, 2010), with parenting by disabled people in general being viewed within a negative framework (Storr, 2007). Whilst some of the women in my study did have significant relapses post childbirth, there was an overwhelming sense that the risks were worth facing, with many women speaking of how they had disregarded medical advice. Moreover what was particularly evident in my study and is lacking in the current literature, is a reflection of the joy and fulfilment that many of my participants had from becoming mothers, despite their symptoms worsening. For example Fiorella and Alessandra were aware of their diagnosis prior to having children, and both later had relapses, but maintained a resolute joy in having a child: “I’d do it again billions of times over! She’s the joy of my life!” (Fiorella).

However, when examining the experiences of the women who did not know their diagnosis prior to becoming pregnant, a few spoke about their doubts as to whether they would have had children had they known their diagnosis. What is significant about their hesitations is that they are based on their fears of not being able to adequately meet their children’s needs and fully participate in their lives, rather than a fear of having a relapse. This differs to other studies, which have found that a major factor in decision making around childbearing was concern for post natal health (Prunty et al., 2008a) and

the impact of pregnancy on MS symptoms (Smeltzer, 2008). This suggests that for my participants, their fears were related to negative societal attitudes as to the ability of disabled women to look after their children, rather than because of concern for their own well-being.

Unlike the participants in Thomas' (1997) study, who did not question medically-defined risks, the women in my study had not heeded medical advice and had gone ahead and had children anyway. This is similar to the findings of Prunty et al's (2008a) study conducted in Australia, who found that the women they interviewed who had children spoke of being defiant at not letting others influence their decision making around having a child. The risk discourse did persist for women in my study though, in women's decisions to have children straight away, such as for Sonia and for Rosa, who described her feelings about being rushed into pregnancy as being akin to "jumping off a sky scraper!" (Rosa). With the lingering link between childbirth and relapses in MS post child birth, and the progressive nature of the disease, it could be considered that making women aware of the risks was related to concern for their medical well-being, rather than to judgemental attitudes on the women's ability to successfully parent a child whilst managing the symptoms of their MS. Other studies have also found that medical advice steered women into rushing their decision making (Prunty et al., 2008a). Further exploration of this specific aspect of whether childless women with MS decided not to have children because of the medical advice (and potentially discouraging attitudes) they were given, would ascertain further the value placed on medical opinion alongside the value of motherhood. Given the value placed on motherhood in Italian society, a cross-cultural comparative study of this issue would potentially highlight socio-cultural differences in decision making.

Additionally, the attitudes of the professionals involved with the women in my study may also have been influenced by the professional's own cultural immersion. The positive advice given to women on having children could be affected by the familiarity of the professionals about the value of motherhood in Italian society, whilst they also had the cultural awareness and reassurance that family members would rally round to provide support to the women in their mothering roles. My findings mainly support this assumption, on the basis of the level of support my participants had from their family members. In contrast, the risk discourse which was presented to the women in medical consultations, could involve a fear that the woman or the child would suffer negative consequences, or that the women were not fit to be mothers, as was the case for the participants in Thomas' (1997) study. A round table discussion by medical professionals on women with MS entering motherhood becoming pregnant was mainly positive (Herndon et al., 2004), although the social barriers women faced were not considered. A study to investigate the attitudes of professionals and their approaches to giving medical advice around pregnancy to women with MS, based on a social model of disability, would further elucidate this issue. This would bridge the current divide in the literature between the medical management for women with MS around pregnancy and childbirth, and the limited number of qualitative studies that have investigated decision making issues from the women's perspectives.

Other than advice from medics on becoming pregnant and managing the course of their disease, very few women referred to having professionals involved in any other areas of their lives, in relation to their MS. In fact, the lack of professional input for the women in my study may have had a positive effect on their mothering as they were not subject to

low confidence and self-esteem that other studies have reported can occur as a consequence of unhelpful support from professionals. Whilst other studies have found that some health professionals may well disempower women in their roles as mothers, this may have been counterbalanced in my study by the family support provided, which was more likely to give them confidence and success in their parenting. This is contrary to many of the women in other studies, who report negative experiences of professional involvement through having had their parenting skills challenged (see for example Wates & Jade, 1999; Olsen & Clarke, 2003).

8.5.3 The Environmental Barriers.

Similar to the findings of other studies conducted with women who had mobility difficulties, many women in my study were prevented from full participation in society and particularly in their children's activities, because of the environmental barriers they faced. This concerned women who were wheelchair users, which has been identified by other studies (Reid et al., 2003). However, it was also an issue for some of my participants who had lesser mobility impairments, due to the poor condition of roads and pavements, as well as the geographical make-up of the city in which most of the women lived, which comprised a mainly vertical set up, being located between the sea and the mountains.

Twoork et al (2007) who conducted a study on quality of life for women with MS, suggest that motherhood presents no practical difficulties for mothers living with MS, although the majority of their study participants had an EDSS (Expanded Disability Status Scale) score of four or less, meaning that they were fully mobile. They acknowledge that further research in this area is needed and it is relevant that the numbers of women in their study with significant levels of impairment were low. For many of the women in my study,

problems were presented to them in the form of environmental barriers. A number of participants spoke about how there were a lack of accessible facilities in their children's school and social venues, which meant that they were unable to accompany their children to after school and holiday clubs, or attend school events. Where facilities existed, often they were broken and unusable, and there was an attitude that any such facilities were 'bonuses' rather than entitlements. These environmental barriers impacted on the women's ability to participate fully in their children's lives, but also had an effect on friendships, as many friendships are formed and maintained through children's activities. Instead, many of the women had to rely on friends and family to assist with accompanying their children to school or activities, or their children had to attend activities on their own, or not take part at all.

Storr (2007) reports that in the majority of studies that have considered issues around disabled parenting, the women lived in deprived areas or had economic difficulties, and many women were unable to undertake housing adaptations due to the prohibitively high costs in doing so. For the women in my study who had mobility impairments, none had had any state funded adaptations to their homes carried out, and no adaptations were observed during the interviews. Some of the women in my study with mobility impairments were unable to leave their homes without friends or family to accompany them, due to the environmental barriers within their home or local community, which is consistent with the findings of Reid et al's (2003) study on women who were wheelchair users. Although some of the women with a higher level of physical impairment spoke about adapting their homes, they all referred to funding such adaptations themselves, rather than expecting any assistance with this from the state. There were therefore potentially high financial costs for many women in my study in funding their own housing

adaptations, but also in purchasing equipment that was not available to them from public services.

Saraceno and Terracina suggest that social inclusion is “not only a matter of rights, but of complex negotiations between different levels of belonging (and different obligations)” (2005:181). For the women in my study, their ‘belonging’ corresponded in part to their perceived identity as mothers and fulfilling the obligations thereof. However, despite them doing their utmost to maintain their role of mother and to continue to be fully included, because of the environmental barriers, their rights to be socially included were not addressed.

Another area of belonging for my participants related to their social relationships. Due to the problems many women had in physically accessing social environments, there was a potential impact on social belonging for my participants. In a round table discussion regarding pregnancy and MS, one professional commented that whilst women with MS often lacked a peer group, pregnant women with MS were even less likely to have one (Herndon et al., 2004). Although this remark is not substantiated further, some of the women in my study also spoke about loss of friendships. As well as the environmental barriers that impacted on this, there was also evidence that loss of friendships was linked to both fear of and realised stigma associated with MS, both directly for the women in my study and for those with whom they associated.

8.5.4 Attitudes & Stigma.

A significant factor that arose in my study was the effect of stigma, both on how the women perceived themselves, and their internalised attitudes; but also how they felt

stigmatised by the attitudes of others towards them. These factors are also relevant to my first research question, in terms of how women perceived themselves as mothers, but will be considered under the remit of attitudinal barriers, as the attitudes of my participants are interlinked with wider societal attitudes. This issue is also pertinent to any differences in the experiences of women who outwardly presented as being disabled, compared to those whose impairments were hidden, and were not necessarily disclosed to others. It is posited that “knowledge on stigma is pivotal in empowerment and efforts against discrimination” (Grytten & Måseide, 2006:196), therefore this concept will be considered in some depth.

Erving Goffman, in his pivotal essay on the concept of stigma, talks of living with a spoiled identity, and how stigma is the “situation of the individual who is disqualified from full social acceptance” (1968:9). He goes on to propose that this spoiled identity can be disseminated to those around the stigmatised person, and in sharing a network of connections with the stigmatised person, they also become stigmatised, what he terms “courtesy stigma”. Many women in my study were precluded from full social acceptance for a variety of reasons, not least the environmental barriers that impacted on their ability to access social environments. However, there was also evidence that some women felt stigmatised and were concerned about their families also being stigmatised on account of them being disabled mothers. Before exploring this in more depth, clarifying the definition of stigma and how I relate stigma to my study is necessary.

Since Goffman’s manifestation of stigma, numerous studies examining the existence of stigma have evolved from a variety of sources (Link & Phelan, 2001) and a clear understanding of the conceptualisation of stigma has been somewhat lost. I will refer to a

model proposed by Bresnahan and Zhuang which puts forward five dimensions which constitute stigma. These are: labelling, negative attribution, separation, status loss, and controllability (2011). Before discussing how these aspects were apparent for many women in my study, I will firstly define my comprehension of the different presentations of stigma and will refer to the delineation by Taft et al which purports that:

- *Enacted stigma* is the actual discriminatory behaviors (sic) by others toward those in the stigmatized group.
- *Perceived stigma* reflects the subjective awareness of stigma.
- *Internalized stigma* reflects the degree to which an individual is in agreement with existing social stigma and stereotypes regarding certain conditions.

(Taft et al., 2013:452)

For the participants in my study enacted stigma was evident in the descriptions of pity many of the women referred to, particularly those women who were wheelchair users or who used walking aids. Pitying looks were synonymous with being a discredited member of society; “I walk really badly, like a zombie, then they [other people] look at me like I must be drunk or stoned...” (Julie). Many women spoke of others being ignorant about disability, and also that people lacked knowledge about MS and its symptoms, with some stating that MS was seen as being indicative of wheelchair dependence. Obliviousness to disability issues and assumptions made about impairments caused the women in my study to be stereotyped by others in society.

Enacted stigma is also manifest in the lack of a political agenda to address environmental barriers which many women described, as the government failed to redress

discrimination caused by the women not having full access to activities that other non-disabled people had, which alludes to an imbalance of power between those who are able to have full access to society and those who cannot.

Many women in my study showed elements of perceived stigma, in that they showed an emotional response to enacted stigma (Taft et al., 2012) by being reluctant to go out into social environments and by expressing their upset at how others treated them as disabled individuals. This was evident in the accounts of many participants who spoke about how they felt others in society did not show them any respect or consideration for their needs as disabled people. For some, this perceived stigma become internalised (also known as self-stigma), which is the process by which individuals endorse stereotypes, consider that these apply to them and believe that they will be devalued (Ali et al., 2012:2122). In this way, some of the women in my study avoided social situations as they considered they would feel degraded by others if they went out and feared pitying looks they might receive from other people. A couple of the women compared their situations to that of criminals; stating that they could understand that punishment was appropriate for criminals, but as they had not committed any offence, they were innocent victims of the views of others. The fact that the women were comparing their situation to that of criminals indicates their perceived stigma from others in society and their internalising of this stigma which demonstrates their ostensive oppression as disabled women.

As women with MS, the participants in my study had already been “labelled” from a medical point of view and indeed by nature of defining inclusion criteria for my study, their participation further reinforced this labelling. Although to some extent we are all labelled, for example as women, as mothers, or with other designated persona,

incumbent with having a label is an indicator of difference. Whilst recognising and identifying themselves with the manifest labels of both woman and mother, some of my participants had more difficulty relating to their medical label of MS, which caused them to view themselves as being different from the norm. In this way, their attitudes towards themselves were related to wider societal attitudes towards their condition. Whether the women shared their "label" of MS with others varied and reflects the negative attributions many women associated with having such a label attached to them. This is most evident in my study when comparing the women who outwardly presented as visibly disabled and those who had hidden impairments. To use Goffman's terminology, the distinction is between those who were 'discredited' as opposed to those who were 'discreditable'. The contrast being between those who, because of their physical attributes, were automatically discredited by those around them, by being labelled as disabled and therefore subject to discrimination. The other group reflects those women who did not present as being disabled outwardly, who had the potential to be discredited, but who were not necessarily so, because they sought to hide some or all of the aspects of their MS. A study carried out with people with MS suggests non-disclosure is a way of maintaining control (Grytten & Måseide, 2005), which has some resonance with the findings of my study. Some of the women in my study concealed some of their impairments or were reluctant to disclose their disease, which suggests negative attributes were associated with having MS. This is also evident as a couple of the women denied the existence of their MS until they got to a stage when their physical symptoms or irrefutable medical evidence meant that their diagnosis was unquestionable. Some women sought to avoid being 'discredited', remaining in the position of being 'discreditable' for as long as possible.

For those who had lesser impairment, who outwardly did not present as being disabled, there was a tendency to view themselves as 'normal' and to avoid asking for help as this was seen as being indicative of dependence and moving away from the perception of normality in their lives. They were attempting to maintain their persona in the "normal world" (Birenbaum, 1970:196) both for themselves and for their families and to avoid being discredited members of society. Some women spoke of how they were reluctant to accept aids and equipment, what could be referred to as "stigma symbols" (Goffman, 1963:66). Linking the use of equipment with reinforcing their persona as disabled people thereby caused some women to refuse aids that would facilitate their independence. Most of the women who spoke about aids and equipment talked about their wish to maintain their independence, and viewed accepting aids as a failing, with few seeing equipment as being enabling and empowering to them in their lives. In this way, women were demonstrating a perceived stigma, assuming they would be discriminated against by others if they outwardly showed signs of being disabled, by using assistive equipment.

This may also be related to the fear of stigma in the role of mother as the women needed to demonstrate that they were 'good mothers' by managing without additional support. This also arose for the participants in Thomas' study (1997) who felt that it was 'a woman's job' to just get on with it, rather than to seek help. This resonates with Goffman's contention that those who are stigmatized might also employ "disidentifiers" (1963:60), by challenging the pre-conceptions that the social world may have about a disabled woman's ability to manage her children without support. In this way, the women in my study who were adamant that they did not want support were 'disidentifying' themselves as dependent disabled people, which is a stereotype others may hold about

them. They were evading being 'separated' from the 'normal' world, again demonstrating their perceived stigma.

Birenbaum (1970) suggests that whether one lives in the 'normal' or the 'stigmatised' world is to some extent dictated by how a person participates in the social world around them. This relates to the loss of status, another dimension of Bresnahan and Zhuang's (2011) model of stigma. Losing status would seemingly stem from the women not being able to participate in the social world, which was largely due to environmental barriers, struggling to find a balance between the normal and stigmatised worlds. However, the accounts of the most impaired women in my study, who were least physically able to access the social world around them, suggested they were less fearful of stigma in their lives. For these women, the reluctance to accept help was less evident, though for some there was an underlying regret that they needed help, but an acceptance that this was needed. The women who were more physically impaired thereby had found a balance between their worlds, they had transcended into the "world of the stigmatised" but were supported by others to participate in "conventional social roles" (Birenbaum, 1970:196) thereby renegotiating their own 'normal' worlds. In this way, the women had delineated their life roles differently and did not express regret at any loss of status, instead redefining themselves: "I don't think I'm a mum with multiple sclerosis, I'm a mum..." (Alessandra). These women had developed "stigma resistance behaviors(sic)" (Taft et al., 452) in that they appeared to be relatively unaffected by 'internalized stigma' (Ritsher et al., 2003) and had moved to a position of self-acceptance as mothers with MS.

The ability of the more impaired women to circumvent some aspects of internalising stigma may also be because those who were more impaired had been further subject to

blatant stigmatising attitudes from others and therefore had become more proficient at managing such social situations and had become adept at stigma management (Goffman, 1963). In point of fact enacted stigma from others in society was apparent for the women in my study who were visibly disabled, in that they described that people stared at them or questioned them about their impairment. Whilst some of the women felt at ease with this, such as Ottavia and Sonia, others were more hostile in their reactions. This invasion of the privacy of the women indicates that they are stigmatised on account of it being seen as acceptable to be approached at will by those who wished to question their condition (Goffman, 1963). Goffman suggests that in such situations, 'the stigmatised' respond with one of two reactions: 'defensive cowering' or 'hostile bravado'. For the women in my study, those who expressed their hesitation in being in public places for fear of other people staring at them, perhaps serve as examples of when women adopted the reaction of 'defensive cowering', in avoiding situations that would subject them to the reactions of others. They had thereby internalised their stigma. Reactions such as that of Fiorella and Erica; "...I was aggressive, like 'what the [bleep] are you looking at?" (Fiorella), demonstrate the 'hostile bravado' some of the women adopted. Whether the women reacted with 'cowering' or 'bravado' also depended on their own assurance as disabled people and whether or not they internalised stigma. For some of the women in my study who internalised their stigma, this also led to them being concerned about courtesy stigma for their children and families, with women speaking about how they were worried their children would be embarrassed to be seen out with them.

However, as Ottavia said "I know that a lot depends on how you present yourself..." The women who were more comfortable in their identity as disabled people were less likely to respond with hostility, but were also unlikely to cower to comments or stares from

others. These women did not internalise stigma and showed stigma resistant behaviours. Alessandra's example of her decorum when she was on holiday when the mothers of children would not let them talk to her, and Ottavia's example of when the woman in the restaurant stared at her when she was not assisting her children give key examples of this. For both of these women, and for some others, they did not avoid social situations and instead integrated as fully as the environmental barriers would allow them to, within society. When people questioned or stared at them, (as many women described), for women who were at ease with their disability, they maintained their dignity and were not drawn into an identity of a 'discredited' person. What is interesting is that those who defied internalising stigma and showed stigma resistant behaviours, were the women who were open and upfront with their families about their MS from the outset. Women who sought to protect their children from the burden of worry about their disability (Reid et al., 2003) demonstrated that they internalised their stigma more than those who were more open in sharing aspects of their MS with their children. Through having the ability to discuss their MS with their husbands and children, the women had 'normalised' their MS and had set it to one side to focus their energies and attention to their valued life roles, indeed they had positive attitudes towards themselves as mothers. These issues have relevance to my first research question as to the factors that influenced the mothering role, but are also interrelated to the discussion in section 8.3.1 about adjustment and communication.

Many of my study participants spoke of how they lived in the present, appreciating their current lives, rather than thinking about the past or pondering the future. This tendency to live in the present and thereby value positive moments (Reynolds & Prior, 2003) may also have contributed to the reported experiences of those women who were

comfortable with their roles and spoke of mainly positive experiences of mothering. These women were content with the significance of “being” rather than solely focusing on “doing” and did not feel an obligation to present as “normal” (Reynolds & Prior, 2003:1228). The women had successfully maintained their roles as mothers, not necessarily through “doing” with their children, but also through “being” with them. In this way these women had become more empowered in renegotiating or maintaining their life roles, which is a factor both in how the women had retained their roles as mothers, but also how they had disregarded potential negative societal attitudes towards them as mothers.

Ritsher et al suggest that “Empowerment is the morale, optimism, self-efficacy or ‘can-do attitude’” (2003:38) which is the contrasting force to internalized stigma. Women who are empowered are more likely to have a sense of ‘controllability’ which is another aspect of stigma. For the women in my study, those who showed a greater command or control over their lives were those who had maintained control in their role of mothers, whether or not this was with the assistance of others. That is, being dependent on others for assistance with child care tasks did not necessarily lead to a loss of control of the mothering role for my participants. Indeed, reliance on others for general assistance was seldom seen as a loss of control, other than for Fiorella and Patrizia who both spoke of feeling somewhat powerless over the support they had. For Fiorella, this was in relation to how her in-laws had taken over the care of her daughter when she was young, and the lack of response to her request for help from public services. For Patrizia, this was due to feeling overwhelmed by her husband “...he’s always hovering around me and I tell him...I’m not a dog on a lead!” (Patrizia). However, the majority of women in my study were more empowered in the support that they had because it was provided by family

members, rather than by public services, but also because many employed their own assistants. They had more control over how their support was delivered and directly employing someone to assist, as opposed to having pre-defined state support is more empowering for disabled people, as many an advocate of the former UK structure of direct payments for disabled people would verify.

8.5.5 Summary on Barriers and the Government Role.

As is evident from the above discussion, there were many links between the barriers faced by my participants in fully partaking in their children's lives and the role of the government in addressing these barriers, both from a policy and attitudinal perspective. Within my study a significant factor affecting the role of the women in being an active part of their children's lives was the environmental barriers they faced, and there was a lack of government action to redress these. If such barriers were eliminated this would avert the fears of the women being unable to fully participate in the lives of their children, which would have a subsequent impact on negative societal and professional attitudes towards the ability of disabled women to successfully parent. Full participation in a society absent of environmental and attitudinal barriers would enhance the lives of all the women in my study who spoke of how they were precluded from their children's lives. It was not the women's symptoms per se that prevented their participation, but instead the barriers that disabled them on account of their impairment. For women with physical impairments which effected their mobility, the lack of accessible buildings and public transport prohibited their full involvement in society, including in their children's lives; and for these women and for those who had hidden impairments, fear of stigmatising attitudes for themselves and their families, also impacted on how they

participated in the lives of their children. My study therefore supports the proposal that many barriers linked with disability are socially constructed, in other words, they are preventable (Prilleltensky, 2004).

8.6 In what ways does this empirical study on the experiences of Italian women with MS contribute to the wider understanding of issues around disability and motherhood?

My final research question considers the contribution my study has made to the current literature and clinical context of disability and parenting, but I will also consider this in relation to how my study has added to the on-going development of IPA research.

8.6.1 Reflections on Purpose.

It is imperative to reflect on whether my study has achieved its fundamental aim of exploring and revealing the lived experience of disabled mothers in Italy. My study used a relatively small sample to highlight the experiences of disabled women, but considered the experiences of these women in some depth. My study can only assert to report on the experiences of women who have MS, but a number of the themes identified relate to issues around being a disabled woman in general, rather than only being relevant to the experience of living with MS.

My study took place in a confined geographical area of Italy and, recognising the differences in welfare provision across the country, women in other areas of Italy may report different experiences. This applies to the socio-cultural differences, but may also impact on the women's experiences of environmental barriers, which were pronounced

for the women in my study, but may be less significant from women living in geographically different regions.

Though seeking to investigate the lives of women with varied levels of impairment, the sampling criteria were not wholly accurate. This was because although the women were selected according to their EDSS score and allocated into the respective group criteria accordingly; some women had not been seen by a neurologist nor had their EDSS score upgraded for some time. This meant that some of the women, namely some in groups 1 and 2, may have in fact been in the group of women with a higher level of impairment. However, whilst the level of impairments of the women presented some interesting contrasts and similarities, it is important to note that the analysis of my study was about disability, not chronic illness (Thomas, 1997), that is, defining disability in terms of the barriers the women faced, rather than viewing the women as being disabled per se, on account of their MS. That said, some of the findings related to 'self and identity' may also have been influenced by the duration of time the women had lived with their MS, which was not specifically explored within my study, as this information was not collated. Additionally, the type of MS the women had was not recorded, which may have impacted on their experiences, particularly in terms of the issues raised within the superordinate theme of 'self and identity'.

The literature that considers disabled women's experiences has tended to focus on the lives of women who chose to have children when they were already disabled (see for example Reid et al., 2003; Prilleltensky, 2004), with rare commentary from women who experienced motherhood pre and post onset of an impairment. In exploring the experiences of women with multiple sclerosis, this study has given an insight into the

experiences of women who knew their diagnosis pre-pregnancy and those who were unaware of their diagnosis or who were asymptomatic prior to pregnancy. Unlike my study, research that has been conducted with women with MS regarding maternity has tended to focus on the impact of pregnancy on disease progression (Twork et al., 2007) rather than on the lived experience of being a mother with MS.

8.6.2 The Audience.

In line with many other phenomenological studies, my research findings are aimed at clinicians and others whose practice would benefit from gaining an insight into how disabled mothers made sense of their experience of living with an impairment (Starks & Trinidad, 2007). One of the major goals of rehabilitation professionals and occupational therapists is to facilitate clients to participate in meaningful, purposeful occupations (Lexell et al., 2009). However, research on engagement in occupation is scarce, with that which has been conducted focusing on performance, neglecting the consideration of the circumstances influencing performance (Lexell et al., 2009). Due to its focus on facilitating an in-depth understanding of human experience within a contemporary cultural context, IPA offers much to both health professionals and researchers, to inform health care policy and practice (Shaw, 2001), and phenomenological studies bridge the practice/research divide for therapists (Finlay, 2011). IPA studies are particularly suited to issues which are of “cross-disciplinary interest” (Cassidy et al., 2011:264), and my study findings are relevant to occupational therapists, psychologists, medics, and other professionals working with disabled women.

My study is also relevant to other professionals working with women with MS, perhaps particularly so for those who are giving advice and support around pregnancy and

mothering. What my study highlights is the value gained from becoming and being a mother, even when women are not able to fully physically participate in this role.

Although research continually moves forward and medical influences on decision making around motherhood for women who have impairments becomes more positive, what is often overlooked is the implicit value of motherhood, rather than the potential negative consequences of being a disabled mother. My study is particularly relevant to the profession of occupational therapy, as the fundamental principle of occupational therapy is that people benefit from being engaged in meaningful occupational roles.

8.6.3 Occupational Well-Being and the Role of Mothers.

In considering the value of my study to occupational therapists, I refer to some of the literature that underpins occupational therapy philosophy and practice. Wilcock (1999) suggests a trilogy of synergising factors that constitute occupation, and purports that having a balance between *doing* and *being* are central to well-being, which will lead to a sense of *becoming*. For the women in my study, I will avoid asserting that some were better adjusted to having MS, as this implicitly suggests that they had become different from the norm and needed to adapt themselves to fit back into a rigid society. Instead, I propose that some women demonstrated that they had found a balance in their role as mothers between *doing* and *being* and so had reached a state of *becoming*. Later writers have added a further dimension of *belonging* being relevant to occupational engagement (Lala & Kinsella, 2011) and others consider all four elements are essential to giving meaning to occupation: *doing, being, belonging and becoming* (Hammell, 2004).

A number of women in my study referred to their achievement of being a mother with MS and likened this to feeling accomplished or proud. These were not necessarily the

women who were able to physically participate in *doing* a great deal of the tasks of mothering. This shifts the focus of the occupation of motherhood to *being* a mother, the value of which is often overshadowed by a focus on the ability *to do* an occupation (Lala & Kinsella, 2011). The element of *belonging* includes social relations and the social environment (Lala & Kinsella, 2011) and some women in my study were fully included in their social environment, although others were more restricted because of environmental barriers or because they were less likely to engage because of internalised stigma. There was therefore not necessarily a direct link between those women who were more physically able to participate in tasks with their children and feelings of fulfilling this life role. Social relationships are perhaps particularly significant for my participants due to the fundamental role of families in their lives. Some of my study participants had renegotiated these relationships, shifting roles and engendering understanding of their condition (or not, in some cases) in family members.

The complex intertwining of doing, being and belonging in the role of motherhood is evident in the accounts of my participants. For those who had successfully negotiated these elements in their lives, either through maintaining their roles or renegotiating them, they showed that they had fulfilled the element of *becoming* in their role of mother and that this is a valued occupational role. This is potentially more so in Italian society, where the role of mother is perhaps given more prominence than in other European countries. As is recognised “When the consequences of impairment are altered through engagement in valued occupations, both the experience and the meaning of disability are altered” (Hammell, 2004:298).

My study has shown the value of the occupational role of mothering for women in Italian society and the barriers that can preclude disabled women from fulfilling their wishes to be fully involved in their occupation as mothers. Occupational therapists both in this cultural setting and others need to recognise the cultural influences on the role of mothers and support women in engaging in this occupation, both by acknowledging the value of *being* a mother, rather than solely focusing on *doing* motherhood. Occupational therapists have a role to play in highlighting and challenging the range of barriers that prevent women from being fully engaged in this occupation, both from the practical perspective and from a socio-political position.

In addition to the relevance of my study findings to occupational therapists and other professionals, my findings were aimed at women as a whole, both disabled and non-disabled, to facilitate a discourse around the experiences of being a woman with a disability in the cultural context of Italy. In this way, I aimed to enable the voices of my participants to be heard by sharing their lived experience with wider society. My study thereby gives a voice to the experience of being a disabled woman in Italy, a previously overlooked group in the academic literature. The value of participating in the study was expressed informally by a number of the participants at the end of our interviews, and is evident in the willingness of all the prospective participants contacted, who all agreed to participate in the study. A quote from Ottavia exemplifies this:

"I have to thank you, I'm very honoured to....participate in this thing, yes...when I read what arrived and I read everything I felt very honoured! So...I have to thank you!" (Ottavia).

These combined audiences thereby acknowledge Morris's (1993) contention that the "personal is political", as my study construes lived experience into socio-political issues

for consideration, by raising issues for both professional consideration and by giving disabled mothers a collective voice.

My study has described and revealed the phenomenon of living as a disabled mother in Italy, so that those who have not experienced this will have a greater appreciation of it (Thorne, 2000). The existing literature recognises that further investigation is needed on the experiences of disabled parents, for example on the quality and levels of assistance disabled women have in order to fulfil their parenting role (Storr, 2007). My study has given an insight into the lack of publicly funded assistance and the high level of family care provided to disabled women in Italy, which gives an understanding of the experiences of disabled mothers who are supported by informal rather than formal care.

Within the wealth of literature concerning family social policy in Italy, the focus has largely been on the area of low fertility, intergenerational support of children and the elderly, and the socio-economic status of young people, with a lack of consideration on issues for disabled people. The Italian feminist literature available in English tends to consider employment, child care provision and historical aspects of feminism; again the relationship of these issues for disabled people is largely overlooked. Therefore, the impact of past and future social policy on issues affecting disabled people in Italy is not represented adequately in the academic literature. For women, there has been little social policy focused on addressing issues of inequality in the workplace and on the division of labour generally. For women who are also disabled, their right to equality will be further compromised on account of the lack of reference to issues for disabled adults in Italy, with the focus being more on children and the elderly. My study has highlighted issues for women who are disabled, showing how the combination of the gender

expectation of roles, perpetuated by the socio-cultural environment, interrelates with their lives as disabled people and the impact of their role as mothers. My study has also emphasised the issues for disabled women around intergenerational support, underscoring previously unexplored factors around the gendered expectations of being providers of care to both children and elderly family members, alongside being recipients of care across these different generations.

In using a native Italian speaker to conduct the interviews, I, as the researcher, cannot contend to have been wholly in control of the conduct of the interviews and choice of wording used in posing questions and prompts. However, the process was as transparent as was practically possible, aiming to demonstrate the trustworthiness of my study and overcome any potential obstacles in presenting a true representation of my participants' voices.

8.6.4 Trustworthiness of My Study

Despite the lack of standardised benchmarks for assessing the quality of qualitative studies, (Curtin & Fossey, 2007), such studies need to be "robust enough to withstand the scrutiny of its readers and its quantitative counterpart (Ball et al., 2011:303). Curtin and Fossey (2007) posit the necessity to use terminology from a qualitative standpoint, rather than apply quantitative concepts to qualitative methodologies, and suggest that qualitative studies should be judged on their trustworthiness. With regard to the trustworthiness of my study, I refer to Yardley's (2000) well recognised characteristics of good qualitative research, which defines four facets. These are sensitivity to context, commitment and rigour, transparency and coherence, and impact and importance.

In addition to Yardley's criteria, I have also considered Curtin and Fossey's quality standards. Two of their criteria refer to "member checking" and "collaboration", and within the chapter on methodology I outlined how the follow up interviews and feedback to my participants provided a means of complying with these standards. Concerning my study's "impact and importance" (Yardley, 2000), the above discussion on the applicability of my study has demonstrated how my study complied with these concepts, by discussing the contribution my study has made to the discourse on disability and parenting, and the potential transferability of my study findings (Curtin & Fossey, 2007).

Curtin and Fossey also suggest a further criterion for judging trustworthiness, is provision of a "thick description" (pp.90) of the context and methods used. This equates to Yardley's description of commitment and rigour, which advises prolonged engagement and immersion with the topic and data, and production of a complete and comprehensive analysis (2000). The analysis and discussion of my findings has provided such a "thick" description of how I applied methods and underpinning methodological paradigms to my study, and the literature search gave a detailed description of the study context. Yardley also refers to the need to show sensitivity to the context, by demonstrating an awareness of the socio-cultural setting, and whilst my literature review corroborates with this aspect, the analysis and discussion also highlighted further socio-cultural factors pertinent to my study.

My compliance with "transparency and coherence" (Yardley, 2000:219) is demonstrated in highlighting the potential complexities of conducting research in a second language and how these have been addressed in my methods, as well as the unanimity between the phenomenological approach to my study and the exploration of lived experience implicit

in my study questions. Reflexivity, another quality benchmark (Curtin & Fossey, 2007), has been addressed within the discussion chapter, with regard to the study findings and will be demonstrated below, by looking at issues to do with language and roles in the interviews.

8.6.5 Language Issues.

Language both constructs and describes the social world in which we live (Temple, 2002), so it was essential, as my study focused on the narrative of my participants, that I gave thorough consideration to issues of language. Acknowledging the relationships between those involved in translation, and the methods used to address the challenges in cross-language studies, strengthens the rigour of a study (Larkin et al., 2007), although there has been relatively little written in the research methods literature on guidance for working with language intermediaries (Edwards, 1998). Temple and Young (2004) advocate for openness regarding the translator role, but acknowledge that this is frequently hidden or disregarded. In line with some other researchers (such as Edwards, 1998; Neufeld et al., 2002; Riessman, 2000; and Temple, 2002; all cited in Temple & Young, 2004) I took a reflexive approach to the researcher/translator roles and engendered open dialogue regarding the potential dilemmas over word choice the translator may have encountered. In this way, I acknowledged the “cultural brokerage” role of the translator, as she considered meaning equivalence (Temple & Young, 2004). I recognised that the translator was not neutral in the process, as I relied on her to give contextual meaning to the words of my participants.

It has been argued that “The information contained in verbal and nonverbal communication exchanges is harder to decipher and retain within the process of

translation, unless active steps are taken to ensure that vital communication is not lost” (Raval & Smith, 2003:23). The potentially problematic issues that are presented in the literature around translation and interpreters can therefore be addressed when the researcher spends time considering the actual processes of the translation. Through establishing a collaborative relationship with the interviewer and the translator; engendering an open reflexive dialogue between all the parties concerned; using back translation to ensure accuracy of translation, following up on issues in the second interviews, and by dynamically involving myself in the interviews, I took active steps to put in place all possible safeguards to ensure effective translation took place. Through exposing the above potential challenges, I have demonstrated my proactive approach in considering issues of translation in my research and how I adopted a reflexive approach, rather than concealing the role of the translator. As Berman and Tyyskä state it is “critical for research to emerge that makes the role of the translator visible” (2010:18).

Temple (2006) draws on a quotation by Fantini (1995:152) which suggests “Those who have never experienced another culture or labored to communicate through a second language are, like the goldfish, often unaware of the milieu in which they have always existed”. Despite the potential complexities of conducting a study in an alternative language as a novice researcher, the above discussion and my methods section demonstrated the processes adopted to address issues of accurate representation and highlights some of the issues that arise in ‘labouring to communicate through another language’. The following section will consider how these issues applied to conducting an IPA study.

8.6.6 Use of IPA in Other Languages.

Despite an increasing expansion in qualitative research being conducted in languages other than English, there has been limited academic debate around issues of interpretation in relation to research discourses and paradigms (Regmi et al., 2010).

Moreover, although it is evident in the literature that cross-language studies using IPA are undertaken (see for example Timotigevic & Breakwell, 2000) there is a failure within such studies to openly acknowledge the role of interpreters or translators around methodological issues. However the role of the researcher in IPA studies has been acknowledged, therefore an important facet to consider was how my role as a researcher and the roles of the interviewer and translator interrelated in my study.

Edwards (1998) places emphasis on the researcher being familiar with the culture of the participants of a study and as I was born and raised in England, undertaking a study in Italy necessitated a consideration of the changed cultural environment in which my study took place. As Anderlini-D'Onofrio (1994) contends, I am "accultured" in the UK and at the time of my study, was a "new immigrant reacculturated" (pp.209), or more likely in the process of being reacculturated into Italy. I am, in the words of Anderlini-D'Onofrio "an expatriate suspended between two cultures" (1994:220). Although I did not share a fluency of the Italian language to enable me to conduct the interviews without a native Italian speaker, having lived in Italy for over two years at the start of my study, I was able to gain an insight and experience of living with the culture of day to day Italian life. In the interviews I was therefore able to hear and understand some key words and phrases used by my participants and this, in combination with my observations of body language, emotional responses and other non-verbal communication, enabled me to take a more active role in the interviews. As Riessman (1993) states "how something is said is as

important as what is said" (in Temple, 2005:6). I learnt to recognise colloquialism, such as when Alessandra used the word "bah" in her interview she was expressing uncertainty; and the word "boh" was used by other women to express their lack of concern about a subject, equivalent to something like "I don't give a damn!"

I also facilitated an active role for myself by introducing myself and my Italian colleague and explaining the reasoning why an additional interviewer was necessary. I also made sure, as far as was practically possible, that the interviews remained a three way conversation, by physically positioning myself within the line of vision of the participants, as seating arrangements of this three way conversation are also relevant to consider (Wallin & Ahlström, 2006). I participated in the interviews by responding with my own body language as appropriate, for example nodding encouragement if a participant looked my way. By adopting these tactics, I aimed to avoid becoming isolated as a researcher, demonstrating my active listening in the process (Edwards, 1998). The value and worth of my attempts to remain active in the interviews was confirmed to me by a comment from a participant during our first set of interviews:

"...but I mean I could see when I looked at you I could see in your eyes that you understand me eh on the whole, you know? Perhaps not each detail, but you know, let's say the most important things you understood, I'm sure because I could see it in your eyes that you did..." (Sonia).

The above quote demonstrates that although I was unable to verbally participate to a great extent in the interviews, my active role was valued by the participants.

Considering the power dynamic between my participants and myself as the researcher, my ability to actively verbally participate in the interview dialogue was limited by my

language inadequacy, which may thereby have lessened any perceived status of my role in the process, which may conceivably facilitate the participants to have a more empowered role in the interviews, which would accord with the aim of my research. By actively seeking this involvement of the interviewer from an early stage and responding to her feedback, I was also trying to avoid any perceptions she may have held of a hierarchy of power, which caused complications in Raval and Smith's (2003) study.

Indeed it is important to recognise the hierarchical roles of power within language (Temple & Young, 2004; Larkin et al., 2007) as "There is no neutral position from which to translate and the power relationships within research need to be acknowledged" (Temple & Young, 2004:164). The translator involved in my study was not directly involved in the interviews and did not meet the participants, or the interviewer. In this respect, she was separate from the research process. However, in terms of her role in the research process, she was very much involved, due to her key role in translating my participants' stories from Italian into English. She was thereby a collaborator in the research process (Larkin et al., 2007) and our working relationship was relevant to my study. Raval and Smith's study (2003) recognised "For any professional alliance to develop, colleagues need to have regular opportunities to work with each other over a reasonable period of time" (Raval & Smith, 2003:17). As stated earlier, through an initial briefing meeting with the interviewer, our relationship started to develop on an equal footing, as we were both learning from each other and there was no perceptible hierarchy of power in our relationship. I attempted to continue this sharing of power, rather than adopting a hierarchical approach to my study, through continued dialogue and responding to any feedback from the interviewer. Prior to each interview, the interviewer and I discussed the details we had on our participant and reflected on the previous interview we had

conducted, sometimes leading to changes in how questions were phrased, or discussion as to what other prompts might be helpful to use. We also had a discussion after each interview, to reflect on how the interview itself had gone and to summarise the information gained. Likewise we had further discussions regarding the interviews when I had received the translated scripts. This was particularly useful if something had been said in the interview that I had not identified at the time, or if I was uncertain that the translator had fully grasped the context of the words.

However, my relationship with the translator started off somewhat differently. My initial correspondence with her was around issues to do with funding, with her tendering for the translation work. This may have unintentionally set into motion a hierarchy of power, with my role deciding on her fate in gaining or losing the tender. Then, having confirmed her position in the study, the next stage in our working relationship involved her translating the first script. The turnaround time for this was very tight, with demands on me from the university in producing this document, in order to meet the requirements of my probationary review. There were also some practical issues for the translator on the lengthy process of transcribing and then translating the recording, alongside her other commitments. Ultimately, the translator was unable to return the completed translation in a timely way, which led to my losing trust in her ability to deliver to the standard I was expecting. Through a subsequent exchange of emails and discussion, expectations were redefined and the translator became more open with me about the demands that she was managing. Simultaneously, pressure in meeting university deadlines for me became less demanding and a more comfortable pace of turnaround for the transcripts could then be followed. This enabled me to take my time in immersing myself in the data from each interview prior to considering the next and gave the translator more time to produce a

thoroughly considered transcript. As the relationship became more trusting, the translator began to take a more active role in the transcripts, often highlighting local dialect and analogies used, and inserting footnotes to explain the context of these. It highlighted to me that although the translator had a lived experience of growing up with a mother with MS and had lived in Italy, a more thorough briefing from me, on the existing literature and the aims of my study would have been helpful prior to commencing the interviews. If practically possible, a face-to-face meeting to initiate dialogue and to clarify expectations on both sides would also have been helpful and may have engendered more equality in the relationship from the start, as was the case between myself and the interviewer. Although as the researcher I defined the topic (Edwards, 1998), the aims of my research, and hence the questions for the interviews, it also transpired that as the interviewer was familiar with working with women with MS in the cultural environment of Italy, that she soon developed the confidence and skills to know when to probe further regarding issues raised that were relevant to the research aims. As Edwards states, as researchers, the basis on which we pursue or abandon issues that arise in the interviews may not necessarily be any better enlightened than that of the person doing the interview (1998:204). Edwards (1998) proposes that interviewers who follow up or probe on issues themselves can be helpful. As mentioned earlier, having reviewed the transcript from the pilot Italian interview, I briefed the interviewer on areas on which she could have probed more and times at which she could have allowed the participant more time to speak before going on to ask the next question. This proved to have been most valuable, as the subsequent interview showed her exploring issues raised by the participant, allowing pauses and silences to more naturally occur, which showed her how the participant spoke of her own accord, without her needing to intervene with another question. Due to the interviewer's inexperience in research interviewing

(although she had experience of interviewing in a clinical setting), she found the technique of allowing for silences and waiting quite challenging, though she was later able to acknowledge how much more facilitative the interviews were, when she paused and gave the participant time to speak. The interviewer's acceptance of silences in the interviews was valuable as "Silence may be as telling as talk" (Booth & Booth, 1996:57), and the pauses in the interviews were reflected in the transcripts. Additionally, the slower speed then adopted in the interviews enabled me to gain a better understanding of the issues being discussed, and this allowed me time to intervene during the interview, to confirm that I had understood correctly and to ask the interviewer to probe deeper on topics that were raised. At the beginning of each interview, the interviewer explained to the participants that I had a higher level of understanding than spoken ability in Italian, and I may therefore intervene during the interviews to clarify my understanding or to ask the interviewer to further explore their responses. However it was rare that I did this, as I did not want to disrupt the flow of the interviews. For these reasons, as previously discussed, reflexive discussion between myself and the interviewer about each interview was undertaken for every interview, to allow for any feedback and discussion on unexpected topics or issues that arose, or that could be further pursued in subsequent interviews.

Hsieh et al's study (2010) found that interpreters were valued for their ability to be active in the interview process, as long as it was conducive to the goals of the team. By establishing dialogue with the translator to clarify her decision making, I initiated her increased active role in the translation. I recognised that she was not just a conduit of information (Raval & Smith, 2003), but was actively involved in meaning making and that

translation needs to be meaning based, rather than a literal translation (Berman & Tyyskä, 2010).

8.6.7 Summary of Reflexions on Methodology.

Starks and Trinidad (2007) suggest that qualitative research is essentially subjective, due to the researcher being the instrument for analysis. However in studies which require the use of a translator, there is also an argument that the translator becomes an instrument of analysis too, through the translating of the narrative from one language to another. My epistemological position is that "...language is more than text alone and (hence) the focus moves to discourse and how people create and describe their social worlds" (Temple, 2006:8). Therefore I was aware that the language my participants used was socially influenced and I needed to be mindful of not misrepresenting the meaning of their words through the translation process. As Temple states "...moving across languages has epistemological and methodological consequences" (2008:357), therefore it was important to consider the translation of my participants words as more than just a technical exercise (Temple, 2008).

Traps determines "In tackling the difficulties and complications of translation, we are confronted with the difficulties and complications of language itself, that opaque medium through which the self and the world around it are constructed" (2009:146). It was therefore essential, with a study focused on the narrative of my participants and with the different language used within my study, that I gave thorough consideration to issues of language and the impact on my methodology.

Considering the boundaries and partnership between myself and the interviewer, we quickly built up a collaborative relationship (Raval & Smith, 2003) and the build-up of an effective working relationship with the translator has been described above. From the outset, I viewed that I would be working with, rather than “using” the interviewer and translator, thereby valuing their roles in the study, rather than concealing them and exploiting their contribution in the process (Edwards, 1998). Through recognising and reflecting on the roles of the interviewer and translator, my study demonstrates the feasibility of undertaking IPA research in another language. This opens up the future possibilities of investigating the lived experience of phenomena for groups whose voices have yet to be heard within the academic literature.

Chapter 9 Conclusion:

The overall aim of my research was to explore the lived experience of disabled mothers in Italy, by listening to the voices of women with multiple sclerosis (MS). The first research question of my study was to identify the factors that impacted on the women's roles as mothers since the onset of their MS. The findings revealed that my participants' perception of their role as mothers was influenced by socio-cultural factors, and this resulted in a high value being placed on the role of motherhood. Some women spoke of how they compared themselves to other mothers or to themselves before their diagnosis of MS and there was evidence that some women struggled with delegating typically defined motherhood tasks to other family members. However, there was also strong evidence that support from family members was the cultural norm, including the role of children in assisting with household tasks. Some women spoke about issues of loss and saw their MS as influential in their day to day lives, speaking of 'fighting a battle' with maintaining control of their MS. Many women also spoke about friendships, for some this was with regard to how friendships were valued and allowed them to participate in social activities, but for other women this was related to how they had lost friendships.

My second research question examined whether the time of diagnosis was relevant to the impact of MS on the women's experience of motherhood. The findings showed that there were concerns about communication with children. In particular the women who were either aware of their MS prior to having children, or were diagnosed when their children were very young, more openly communicated with their children about their MS and their children had naturally adjusted to having MS in their lives. In contrast, for those women whose children had been older when they were diagnosed, there was more

difficulty with communication. For the women who were already diagnosed when they chose to have children, some of whom had been discouraged by their doctors, they showed how they prioritised the role of motherhood over any fear of having a relapse.

My third research question considered the ways in which wider influences in Italian society, such as the church and the legacy of a government led by Silvio Berlusconi, impacted on the lived experiences of disabled women in Italian society. Many women highlighted the lack of financial and practical support from the government, and had little belief that the government understood the issues for them as disabled people, or had any intention of redressing these in the future.

The lack of government support also fed into my fourth research question regarding how external barriers, such as the environment, society or attitudes, impacted on the women's experience of being disabled mothers. Findings showed a lack of state funded hands on support, or resources such as equipment, which led to the majority of women self-funding these or managing without. This was also influenced by the lack of professional involvement in the lives of the women with regard to assisting them with accessing any resources. Many women spoke of how environmental barriers prevented them from being fully involved in their children's lives, including inaccessible buildings and public transport. Another external barrier related to the attitudes of others in society, with many women speaking about how they were pitied by others, which led to them feeling stigmatised, or expressing concern about how their children might also be stigmatised on account of their MS.

My final research questions concerned the ways in which this empirical study on the experiences of Italian women with MS contributes to the wider understanding of issues around disability and motherhood. Within the general paucity of studies on the experiences of disabled mothering the voices of women in Italy have not previously been defined in the literature and my study has contributed to this knowledge base. My study shows that the experience of being a mother with MS in Italy varies depending on how women are able to engage in this valued occupation. It demonstrates the ways in which my participants had maintained their role, and the barriers that they had to tackle in doing so. These barriers consisted of physical barriers which prevented some of my participants from accessing environments their children went to; but also wider social barriers, such as the lack of a political agenda in recognising their needs as disabled mothers and redressing the inequalities they faced.

The lack of positive socio-political action to ensure equality for my participants had a negative effect on how others in society viewed them, and these attitudinal barriers led to some of my participants feeling stigmatised internally and viewing themselves as different. However, the vast majority of my participants were positively supported in their role of mother by their family members and some indicated that they had found an assured balance in receiving care, alongside maintaining their highly valued role as carer for their children. The findings of my study are therefore highly relevant to occupational therapists, whose role it is to facilitate involvement in valued meaningful occupations. However, my findings also have a wider impact in terms of making a contribution to the discourse on disabled parenting.

My research fulfils the focus of qualitative research and in particular of IPA in enhancing knowledge, rather than providing causal explanation (Clarke, 2009). There is relatively little research universally regarding the experiences of disabled parents (Olsen & Clarke, 2003), and my study enables not only the exposure of so far unidentified experience, but also enables shared aspects of the experience of individuals within different cultural settings, considering the “external forces within a culture” (Shaw, 2001:49). That is, the experience of being a disabled person within the cultural context of Italy has been explored and has enabled an insight into how Italian culture influences lived experience. This approach is harmonious with the fundamental beliefs of occupational therapy practice, which perceives people as being entrenched within a socio-cultural context (Clarke, 2009).

During the three years I have lived in Italy, whilst undertaking my research, I have been reflexive in my studies, as is conducive to both my clinical practice and the use of IPA. It has only been whilst writing up my thesis that I have come to realise that throughout my time in Italy, I have gradually adopted a more anthropological insight to my research, having now gained a much greater cultural insight into the country in which I live and have undertaken my fieldwork.

Whilst drawing to a close with my writing up of the discussion of my findings, a friend passed away. Although born in England, she was married to an Italian and had lived in Italy for almost twenty years. I met her when I first moved to Italy, and I gradually realised that she was a disabled woman. When we spoke about my research, she suggested I could use her as a case study and on reflection, this was a wasted opportunity. Due to work and family commitments our face-to-face contact was intermittent and we kept in

touch mainly by text messages and phone calls. When she died, I was not even aware that her cancer had returned, and, as it later turned out, neither had many people. During the time I knew her and throughout the period of what turned out to be her untimely death, my friend's commitment to her children never faltered. Her role as a mother was infallible. Her children arrived at school every day, bright and fresh, and always with a smile on their faces, even during her dying days. She ensured they attended every school function and after school activity, though her physical impairment prevented her from attending with them. Always immaculately presented herself, both physically and emotionally, my friend did not seek to disguise her impairment, and did not engender pity or ask for help from others. Her family provided her with all the support she needed, aided by long standing friends and the private help she employed.

At her funeral, her husband and children maintained their dignity and decorum, greeting attendees and standing side-by-side unfailingly. It was only after her funeral that I realised what I had witnessed in my friend and her family throughout the time I had known her. There is a concept in Italy known as the "la Brutta Figura", literally, "the poor figure". Its existence is not acknowledged in the English speaking academic discourse, but it is there in Italian society, in its culture, and in its people. Its existence is both explicit in conversations and the media, but also implicit in the culture and disposition of the people. "Fare la brutta figura" is to show oneself up, avoiding doing so is what the British might refer to as "keeping a stiff upper lip" or "putting on a brave face". But avoiding the "brutta figura" does not really match either of these descriptions; it is about loving and respecting your family and maintaining solidarity within it, in the privacy of solid kinship relationships. It is about keeping your dignity and not "letting the side down"; ultimately showing your strength as a family unit. What I had witnessed in the experience of

knowing my friend and in meeting and speaking with many of the disabled mothers during my interviews epitomised these features. Families pulling together, using their own resources, sometimes avoiding social situations and sometimes just facing up to them despite the chance of stigmatising responses from others. Not complaining, at times suffering in silence, and sacrificing one's own well-being for the welfare of their children shows the commitment of my friend and the women in my study in maintaining their roles as mothers.

Having had a stroke as a young mother at the age of twenty seven, I was fully aware of my pre-conceptions of disabled mothering, which were also influenced by my clinical work. However, in acknowledging and reflecting on my pre-existing perceptions of disability and motherhood, as is consistent with IPA, I had perhaps overlooked my existing understanding of my own cultural and social upbringing as a woman and my role as a mother. Having used IPA to explore the experiences of women in their mothering role in Italy, my understanding of life as a disabled mother in Italy has changed dramatically. I had gone into my study expecting to highlight the barriers the women faced and the discrimination they were subject to, both as women and disabled people. I found that the mothers I met were indeed subject to stigma, poorly resourced by social policy and statutory services, and disabled by environmental and attitudinal barriers in society. However, what has also transpired is the enormity of the value of roles and responsibilities within families; both to the women in their roles as mothers, but also to the level of intergenerational support that is being provided to many disabled mothers in this country. In my study, many women had found the balance in maintaining their mothering role despite all the barriers and discrimination they faced, some with more

support than others, but all of them aspiring to avoid “la brutta figura” and prioritising their role as a mother.

As my study has progressed, my motivation has been augmented by the socio-political culture of the environment in which I now live and the life experiences both for disabled people, and also for women, particularly in their mothering role. My academic interest has therefore broadened from not only the experience of disability, but also the social make up of family life in Italy and the gendered expectations that women encounter. This, I consider, has led to an investigation of a relatively unexplored area of academic enquiry and I hope will have some impact and increased awareness of exposing the lived experience for life as a disabled mother in Italy.

References:

Ali, A.; Hassiotis, A.; Strydom, A. & King, M. (2012) Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities*. Vol.33(6). Pp. 2122–2140.

Alvanoudi, A. (2009). Travelling between languages and disciplines: linguistic and interdisciplinary translation practices in Women's/Gender Studies. *Graduate Journal of Social Science*. Vol.6(3). Pp.20-39.

Anderlini-D'Onofrio, S. (1994) I Don't Know What You Mean by 'Italian Feminist Thought.' Is Anything Like That Possible? In *Feminine Feminists: Cultural Practices in Italy*. Jeffries, G.M. (ed). University Of Minnesota Press.

ANED Academic Network of European Disability Experts accessed from
<http://www.disability-europe.net/> on 04.09.2011.

ANED Academic Network of European Disability Experts accessed from
<http://www.disability-europe.net/content/facts-and-figures-13> on 9.8.13.

Ball, E.; McLoughlin, M.; & Darvill, A. (2011) Plethora or paucity: A systematic search and bibliometric study of the application and design of qualitative methods in nursing research 2008–2010. *Nurse Education Today*. Vol.31(3). Pp.299-303.

Banks, P. & Pearson, C. (2004) Parallel lives: younger stroke survivors and their partners coping with crisis. *Sexual & Relationship Therapy*. Vol. 19(4). Pp.413-429.

Barnes, C. & Mercer, G. (1996). Chapter 1. Exploring the Divide. In *Exploring the Divide: illness and Disability*. Leeds: The Disability Press.

Barnes, C. & Mercer, G. (Eds.). (2004) *Disability Policy and Practice: Applying the Social Model*. The Disability Press. Leeds.

Barnes, C. (1996) The Social Model of Disability: Myths and Misconceptions. Accessed from The Disability Archive UK
<http://www.leeds.ac.uk/disabilitystudies/archiveuk/Barnes/Coaliton.pdf> on 24.11.2012.

Barnes, C. (2003) What a Difference a Decade Makes: reflections on doing “emancipatory” disability research. *Disability & Society*. Vol.18 (1). Pp.3-7.

Bell, M. (2008) The Implementation of European Anti-Discrimination Directives: Converging towards a Common Model? *The Political Quarterly*. Vol. 79(1). Pp. 36-44.

Berman, R.C. & Tyyskä, V. (2011) A Critical Reflection on the Use of Translators/Interpreters in a Qualitative Cross- Language Research Project. *International Journal of Qualitative Methods*. Vol. 10(2). Pp.178-190.

Bettio, F. & Plantenga, J. (2004) Comparing Care Regimes in Europe. *Feminist Economics*. Vol.10(1). Pp.85-113.

Bettio, F.; Simonazzi, A. & Villa, P. (2006) Change in care regimes and female migration: the “care drain” in the Mediterranean. *Journal of European Social Policy*. Vol.16 (3). Pp. 271–85.

Bickenbach, J.E. (2009) Culture and the UN Convention. *Disability and Rehabilitation*. Vol. 31(14). Pp. 1111–1124.

Biggerstaff, D.L. & Thompson, A.R. (2008) Interpretative Phenomenological Analysis (IPA): A Qualitative Methodology of Choice in Healthcare Research. *Qualitative Research in Psychology*. Vol. 5(3). Pp214-224.

Birenbaum, A. (1970) On Managing a Courtesy Stigma. *Journal of Health and Social Behavior*. Vol. 11(3). Pp. 196-206.

Blackford, K.A. (1999) A Child’s Growing Up with a Parent Who Has Multiple Sclerosis: theories and experiences. *Disability & Society*. Vol. 14(5). Pp.673-685.

Boeri, T. & Ferrera, M. (2001) EU Social Policies: Challenges and Opportunities for Italy. *The International Spectator*. Vol.36(3). Pp.77-88.

Bogosian, A.; Moss-Morris, R.; Bishop, F.L. & Hadwin, J. (2011) How do adolescents adjust to their parent's multiple sclerosis?: An interview study. *British Journal of Health Psychology*. Vol.16(2). Pp.430-444.

Booth, T. & Booth, W. (1994) *Parenting under pressure. Mothers and fathers with learning difficulties*. Open University Press. Buckingham. U.K.

Booth, T. & Booth, W. (1996) Sounds of Silence: Narrative research with inarticulate subjects. *Disability & Society*. Vol. 11(1). Pp.55-70.

Bornstein, M.H.; Maurice Haynes, O.; Hiroshi, A.; Galperin, C.; Maital, S.; Ogino, M.; Painter, K.; Pascual, L.; Pecheux, M.; Rahn, C.; Toda, S.; Venuti, P.; Vyt, A. & Wright, B. (1998) A Cross-National Study of Self-Evaluations and Attributions in Parenting: Argentina, Belgium, France, Israel, Italy, Japan and the United States. *Developmental Psychology*. Vol.34 (4). Pp.662-676.

Bowen, C.; MacLehose, A. & Beaumont, J.G. (2011) Advanced multiple sclerosis and the psychosocial impact on families. *Psychology & Health*. Vol.26(1). Pp.113-127.

Bramley, N. & Eatough, V. (2005) The experience of living with Parkinson's disease: An interpretative phenomenological analysis case study. *Psychology & Health*. Vol.20. Pp. 223-235.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*. Vol.3(2).Pp.77-101.

Brensnahan, M. and Zhuang, J. (2011) Exploration and validation of the dimensions of stigma. *Journal of Health Psychology*. Vol.16(3). Pp.421–429.

Brocki, J.M. & Wearden, A.J. (2006) A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*. Vol.21. Pp. 87–108.

Bulter, J. (1990) Gender Trouble. New York. Routledge. In Mallon, Ron, "Naturalistic Approaches to Social Construction", *The Stanford Encyclopedia of Philosophy (Winter 2008 Edition)*, Edward N. Zalta (ed.)

<http://plato.stanford.edu/archives/win2008/entries/social-construction-naturalistic/>

Bunch, C. (1988) Making common cause: diversity and coalitions in McEwen, C. & O'Sullivan, S. (eds). *Out the Other Side*. London. Virago, In Morris, J. (1993). *Feminism and Disability*. *Feminist Review*. Vol. 43. Pp.57-70.

Bury, M. (2001) Illness narratives: fact of fiction? *Sociology of Health and Illness*. Vol.23(3). Pp.263-85.

Cahill, M.; Connolly, D. & Stapleton, T. (2010) Exploring occupational adaptation through the lives of women with multiple sclerosis. *British Journal of Occupational Therapy*. Vol.73(3). Pp. 106-115.

Carnaby, S. (1997) A Comparative Approach to Evaluating Individual Planning for People with Learning Disabilities: challenging the assumptions. *Disability & Society*. Vol.12 (3). Pp.381-394.

Cassidy, E.; Reynolds, F.; Naylor, S. & De Souza, L. (2011) Using interpretative phenomenological analysis to inform physiotherapy practice: An introduction with reference to the lived experience of cerebellar ataxia. *Physiotherapy Theory & Practice*. Vol. 27(4). Pp. 263-277.

Clark, L. & Marsh, S. (2002) Patriarchy in the UK: The Language of Disability. Accessed from the Leeds Disability Archive. <http://www.leeds.ac.uk/disability-studies/archiveuk/Clark,%20Laurence/language.pdf> on 17.09.2011.

Clarke, C. (2009) An Introduction to Interpretative Phenomenological Analysis: a Useful Approach for Occupational Therapy Research. *British Journal of Occupational Therapy*. Vol.72(1).Pp.37-39.

Coulter, A. & Magee, H. (eds.). (2003) *The European Patient of the Future*. Chapter 4: Italy. Open University Press. England.

Craig, L. & Mullan, K. (2010) Parenthood, Gender and Work-Family Time in the United States, Australia, Italy, France and Denmark. *Journal of Marriage and Family*. Vol. 72. Pp. 1344-1361.

Creswell, J.W. (2007) *Qualitative Enquiry and Research Design: Choosing among Five Approaches*. 2nd edn. Thousand Oaks. CA. Sage.

Cronin-Davis, J.; Butler, A. & Mayers, C.A. (2009) Occupational therapy and interpretative phenomenological analysis: comparable research companions? *British Journal of Occupational Therapy*. Vol.72(8). Pp.332-337.

Crotty, M. (1998) *The Foundations of Social Research: Meaning and Perspective in the Research Process*. London. Sage Publications.

Culler, K.H.; Jasch, C. & Scanlan, S. (1994) Child care and parenting issues for the young stroke survivor. *Topics in Stroke Rehabilitation*. Vol. 1(1). Pp. 48-64.

Curtin, M. & Fossey, E. (2007) Appraising the trustworthiness of qualitative studies: Guidelines for occupational therapists. *Australian Occupational Therapy Journal*. Vo.54. Pp.88-94.

Dalla Zuanna, G. (2001) The banquet of Aeolus: A familistic interpretation of Italy's lowest low fertility. *Demographic Research*. Vol.4(5).Pp.133-162.

David, M. & Sutton, C.D. (2004) *Social Research. The Basics*. London, Sage.

De Judicibus, M.A.& McCabe, M.P. (2004) The Impact of Parental Multiple Sclerosis on the Adjustment of Children and Adolescents. *Adolescence*. Vol.39(155). Pp.551-569.

De Rose, A.; Racioppi, F. & Zanatta, A.L. (2008) Italy: Delayed adaptation of social institutions to changes in family behaviour. *Demographic Research*. Vol. 19(19).Pp. 665-704.

Disabled Parents Network. Accessed from www.disabledparentsnetwork.org.uk on 04.05.2010.

Eatough, V.; & Smith, J.A. (2008) Interpretative phenomenological analysis. In: Willing C, Stainton-Rogers W (eds). Pp. 179–194. *The Sage Handbook of Qualitative Research in Psychology*.

Edwards, R. (1998) A critical examination of the use of interpreters in the qualitative research process. *Journal of Ethnic and Migration Studies*. Vol.24(1). Pp. 197-208.

Ehlers-Flint, M.L. (2002) Parenting Perceptions and Social Supports of Mothers with Cognitive Disabilities. *Sexuality & Disability*. Vol.20 (1). Pp.29-51.

EMSP European Multiple Sclerosis Platform (2004) *Recommendations on Rehabilitation Services for Persons with Multiple Sclerosis in Europe*. Accessed from <http://www.emsp.org/attachments/article/134/4rehabilitation08.pdf> on 22/01/2013

Equality Italia. Accessed from <http://www.equalityitalia.it/cs-disabilita-e-scuola-simona-clivia-zucchett-equality-italia-dal-pdl-uno-schiaffo-in-pieno-viso-a-tutti-i-disabili%e2%80%9d.html> on 31.05.2011.

Esposito, N. (2001) From Meaning to Meaning: The Influence of Translation Techniques on Non-English Focus Group Research. *Qualitative Health Research*. Vol.11(4). Pp.568-579.

Eurostat (2003) *Labour reserve in Europe in Spring 2001*. Accessed from http://epp.eurostat.ec.europa.eu/cache/ITY_PUBLIC/3-15072003-AP/EN/3-15072003-AP-EN.HTML.

Fade, S. (2004) Using interpretative phenomenological analysis for public health nutrition and dietetic research: a practical guide. *Proceedings on the Nutrition Society*. Vol.63.Pp.647-653.

Fantini, A.E. (1995) Introduction – Language, Culture And World View: Exploring The Nexus. *International Journal of Intercultural Relations*. Vol.19. pp.143-153. In Temple, B. (2006). Representation across languages: biographical sociology meets translation and interpretation studies. *Qualitative Sociology Review*. Vol. 2(1). Pp. 7-21.

Farber, R.S. (2000) Mothers With Disabilities: In Their Own Voice. *The American Journal of Occupational Therapy*. Vol. 54(6). Pp.260-268.

Feldman, S. (1999) Please don't call me 'dear': older women's narratives of health care. *Nursing Inquiry*. Vol. 6 (4) Pp.269-276.

Finlay, L. (1999) Applying phenomenology in research: Problems, principles and practice. *British Journal of Occupational Therapy*. Vol. 62. Pp.299-306.

Finlay, L. (2002) "Outing" the Researcher: The Provenance, Process, and Practice of Reflexivity. *Qualitative Health Research*. Vol.12(4).Pp.531-545.

Finlay, L. (2003) The intertwining of body, self and world: A phenomenological study of living with recently-diagnosed multiple sclerosis. *Journal of Phenomenological Research*. Vol.34(2).Pp.157-178.

Finlay, L. (2008) A dance between the reduction and reflexivity: Explicating the "phenomenological psychological attitude." *Journal of Phenomenological Psychology* Vol.39. Pp.1–32.

Fondazione Censis (2010) Le Disabilita Oltre L'Invisibilita Istituzionale. Accessed from <http://www.censis.it/2010>

Francescutti, C.; Frattura, L.; Troiano, R.; Gongolo, F.; Martinuzzi, A.; Sala, M.; Meucci, P.; Raggi, A.; Russo, E.; Buffoni, M.; Gorini, G.; Conclave, M.; Petrangeli, A.; Solipaca, A. & Leonardi, M. (2009a) Towards a common disability assessment framework: theoretical and methodological issues for providing public services and benefits using ICF. *Disability and Rehabilitation*. Vol. 31(S1). Pp.8-15.

Garelli, F. (2007) The public relevance of the church and Catholicism in Italy. *Journal of Modern Italian Studies*. Vol.12(1). Pp.8-36.

Garg, A. (2005). Interview Reflections: A First Generation Migrant Indian Woman
Researcher Interviewing a First Generation Migrant Indian Man. *Journal of Gender Studies*. Vol. 14(2). Pp. 147–152.

Giannini Quinn, R. (2004) Mothers, Molls, and Misogynists: Resisting Italian American Womanhood in *The Sopranos*. *The Journal of American Culture*. Theme Issue. Vol.27(2). Pp. 166-174.

Giordano, A.; Mattarozzi, K.; Pucci, E.; Leone, M.; Casini, F.; Collimedaglia, L. & Solari, A. (2008) Participation in medical decision-making: Attitudes of Italians with multiple sclerosis. *Journal of the Neurological Sciences*. Vol.275.Pp. 86-91.

Giorgi, A. (2010) Phenomenology and the Practice of Science. *Existential Analysis*.

Vol.21(1).Pp.3-22.

Giorgi, A. (2011) IPA and Science: A Response to Jonathan Smith. *Journal of*

Phenomenological Psychology. Vol.42.Pp.195-216.

Glaser, K. & Tomassini, C. (2000) Proximity of Older Women to Their Children: A

Comparison of Britain and Italy. *The Gerontologist*. Vol.40(6). Pp.729-737.

Glass, T.A., Matchar, D.B., Belyea, M., Feussner, J.R. (1993) Impact of social support on outcome in first stroke. *Stroke*. Vol. 24 Pp.64-70.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. London.

Penguin.

Goodinge, S. (2000) *A jigsaw of services. Inspection of services to support disabled adults in their parenting role*. Department of Health.

Green, J. & Thorogood, N. (2005) *Qualitative Methods for Health Research*. Sage

Publications. London.

Grue, L. & Laerum, L.T. (2002) 'Doing Motherhood': some experiences of mothers with physical disabilities. *Disability & Society*. Vol. 17(6). Pp.671-683.

Grytten, N. & Måseide, P. (2005) What is expressed is not always what is felt. Coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis. *Chronic Illness* 1. Pp.231–243.

Grytten, N. & Måseide, P. (2006) When I am together with them I feel more ill: The stigma of multiple sclerosis experienced in social relationships. *Chronic Illness* 2. Pp. 195–208.

Guerra, S.S. (2013) Management of psychosocial adjustment among people with multiple sclerosis: a critical analysis. *British Journal of Neuroscience Nursing*. Vol. 9(2). Pp.89-92.

Gulick, E.E. & Kim, S. (2004) Postpartum Emotional Distress in Mothers With Multiple Sclerosis. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*. Vol.33(6). Pp. 729-738.

Hammell, K.W. (2004) Dimensions of Meaning in the Occupations of Daily Life. *Canadian Journal of Occupational Therapy*. Vol.71. Pp.296-305.

Harrison, T.C. & Stuifbergen, A. (2005) A Hermeneutic Phenomenological Analysis of Aging with a Childhood Onset Disability. *Health Care for Women International*. Vol. 26(8). Pp.731–747.

Hefferon, K. & Gil-Rodriguez, E. (2011) Interpretative Phenomenological Analysis. *The Psychologist*. Vol.24(10). Pp. 756-759.

Herdon, R.M.; Keating, M.; Miller, D.; Smelzer, S.C.; Ward, N.; and Wollin, J. (2004)

Pregnancy and MS: A Roundtable Discussion. *International Journal of MS Care*. Vol.6(4). Pp.140-143.

Hessen, C.; Kasper, J.; Segal, J.; Köpke, S.; & Mühlhauser, J. (2004) Decision role preferences, risk knowledge and information interests in patients with multiple sclerosis. *Multiple Sclerosis*. Vol.10. Pp.643-650.

Hughes, B.; McKie, L.; Hopkins, D. & Watson, N. (2005) Love's Labours Lost? Feminism, the Disabled People's Movement and an Ethic of Care. *Sociology*. Vol. 39(2). Pp.259-275.

Hurst, R. (2000) To Revise or Not to Revise? *Disability & Society*. Vol. 15(7). Pp.1083-1087.

Hsieh, E.; Hyejung Ju, H.; & Kong, H. (2010) Dimensions of Trust: The Tensions and Challenges in Provider–Interpreter Trust. *Qualitative Health Research*. Vol. 20(2). Pp.170–181.

Irvine, H.; Davidson, C.; Hoy, K. & Lowe-Strong, A. (2009) Psychosocial adjustment to multiple sclerosis: exploration of identity redefinition. *Disability & Rehabilitation*. Vol. 31(8). Pp.599-606.

James, K.S. (2011) On becoming a researcher in the practice context. *OT News*. July. Pp.31.

Jones, A. (2001) A condensed history of the phenomenology: the first and second phases from Franz Brentano to Hans-Georg Gadamer. *Nurse Researcher*. Vol.8(4).Pp.65-75. In Pringle, J.; Hendry, C.; and McLafferty, E. (2011a) Phenomenological approaches: challenges and choices. *Nurse Researcher*. Vol.18(2).Pp.7-18.

Jootun, D.; McGhee, G. & Marland, G.R. (2009) Reflexivity: promoting rigour in qualitative research. *Nursing Standard*. Vol.23(23).Pp.42-46.

Kapborg, I. & Berterö, C. (2002) Using an interpreter in qualitative interviews: does it threaten validity? *Nursing Inquiry*. Vol. 9(1). Pp.52–56.

Kelley, S.D.; Sikka, A.; & Venkatesan, S. (1997) A review of research on parental disability: implications for research and counselling practice. *Rehabilitation Counselling Bulletin*. Vol.41 (2). Pp. 105-21.

Kent, D. (2002) Beyond Expectations: Being Blind and Becoming a Mother. *Sexuality & Disability*. Vol. 20(1). Pp. 81-88.

Kersten, P.; McLellan, D.L.; Gross-Paju, K.; Grigoriadis, N.; Bencivenga, R.; Beneton, C.; Charlier, M.; Ketelaer, P. & Thompson, A.J. (2000) A questionnaire assessment of unmet needs for rehabilitation services and resources for people with multiple sclerosis: results of a pilot survey in five European countries. *Clinical Rehabilitation*. Vol.14. Pp.42-49.

- Kersten, P.; Low, J. T. S.; Ashburn, A.; George, S.L. & McLellan, D.L. (2002) The unmet needs of young people who have had a stroke: results of a national UK survey. *Disability and Rehabilitation*. Vol. 24(16). Pp.860-866.
- Keusch, G.T.; Wilentz, J. & Kleinman, A. (2006) Stigma and global health: Developing a research agenda. *The Lancet*. Vol.367(9509). Pp.525–527.
- Kostanjsek, N. (2009) Implementation of ICF and ICF-CY in Italy. *Disability and Rehabilitation*. Vol.31(S1). Pp.S1-S3.
- Kwakkel, G.; Wagenaar, R.C.; Kollen, B.J. & Lankhorst, G.J. (1996) Predicting disability in stroke – A critical review of the literature. *Age and Ageing*. Vol. 25 Pp.479-489. in Palmer, S. & Glass, T.A. (2003) Family Function and Stroke Recovery: A Review. *Rehabilitation Psychology*. Vol. 48(4) Pp.255-265.
- Lala, A.P. & Kinsella, E.A. (2011) Phenomenology and the Study of Human Occupation. *Journal of Occupational Science*. Vol.18(3.) Pp.195-209.
- Larkin, M.; Watts, S. & Clifton, E. (2006) Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*. Volume 3(2).Pp.102-120.
- Larkin, P.J.; Dierckx de Casterle, B. & Schotsmans, P. (2007) Multilingual Translation Issues in Qualitative Research: Reflections on a Metaphorical Process. *Qualitative Health Research*. Vol.17(4). Pp.468-476.

Lexell, E.M.; Lund, M.L. & Iwarsson, S. (2009) Constantly Changing Lives: Experiences of People with Multiple Sclerosis. *American Journal of Occupational Therapy*. Vol.63(6). Pp.772-781.

Link, B.G. & Phelan, J.C. (2001) Conceptualizing Stigma. *Annual review of sociology*. Vol. 27.Pp.363–385.

Lipson, J.G. & Rogers, J.G. (2000) Pregnancy, Birth and Disability: Women's Health Care Experiences. *Health Care for Women International*. Vol.21.Pp 11-26.

Llewellyn, G. (1995) Relationships and social support: Views of parents with mental retardation/intellectual disability. *Journal of Mental Retardation*. Vol.33. Pp.349-363. In Kelley, S.D.; Sikka, A. & Venkatesan, S. (1997) A review of research on parental disability: implications for research and counselling practice. *Rehabilitation Counselling Bulletin*. Vol. 41(2). Pp.105-21.

Llewellyn, G. (2013) Parents with Intellectual Disability and Their Children: Advances in Policy and Practice. *Journal of Policy and Practice in Intellectual Disabilities*. Vol.10(2). Pp. 82-85.

Llewellyn, G. & McConnell, D. (2003) Mothers with Learning Difficulties and their Support Networks. *Journal of Intellectual Disability Research*. Vol.46(1). Pp.17-24.

- Llewellyn, G.; Traustadóttir, R.; McConnell, D. & Björg Sigurjónsdóttir, H. (2010) *Parents with Intellectual Disabilities: Past, Present and Futures*. Wiley Blackwell, UK.
- Lloyd, M. (1992) Does She Boil Eggs? Towards a Feminist Model of Disability. *Disability, Handicap & Society*. Vol.7(3). Pp.207-728.
- Lloyd, M. (2001) The Politics of Disability and Feminism: Discord or Synthesis? *Sociology*. Vol.35(3). Pp.715-718.
- Mabilia, M. (2010) Contrasting Tanzanian and Italian Perspectives on Motherhood and Mothering. *Suomen Antropologi: Journal of the Finnish Anthropological Society*. Vol.35(4). Pp.35-41.
- Mackenzie, A.E. (1994) Evaluating ethnography: considerations for analysis. *Journal of Advanced Nursing*. Vol.19(4). Pp.774-781.
- Malacrida, C. (2009) Performing motherhood in a disablist world: dilemmas of motherhood, femininity and disability. *International Journal of Qualitative Studies in Education*. Vol.22(1). Pp.99-117.
- Mallon, R. (2008) Naturalistic Approaches to Social Construction. *The Stanford Encyclopedia of Philosophy (Winter 2008 Edition)*. Zalta, E.N. (ed.)
<http://plato.stanford.edu/archives/win2008/entries/social-construction-naturalistic/>.

Marangoni, F. (2011) The Premature End of the Fourth Berlusconi Government: An Updating of Indicators of the Government's Legislative Performance and Productivity. *Bulletin of Italian Politics*. Vol.3(2). Pp.357-369.

McCue, K. (1995) Your Kids and your MS. *Inside MS*. Vol.13(2). Pp.8-13.

McKeever, P.; Angus, J.; Lee-Miller, K. & Reid, D. (2003) 'It's More of a Production': accomplishing mothering using a mobility device. *Disability & Society*. Vol.18(2). Pp.179-197.

McNary, M.E. (1999) Themes arising in the motherhood decision for women with multiple sclerosis: an exploratory study. *Journal of Vocational Rehabilitation*. Vol.12. Pp.93-102.

Meadow-Orlans, K.P. (2002) *Parenting With a Sensory or Physical Disability*. Chapter 11 in Bornstein, M.H. (ed) *Handbook of Parenting. Volume 4. Social Conditions and Applied Parenting*. Second Edition. Lawrence Erlbaum Associates. New Jersey.

Micangeli, A.; Puglisi, A. & Vignola, R. (2007) Report on the employment of disabled people in European countries. Academic Network of European Disability Experts.

Accessed from <http://www.disability-europe.net/content/aned/media/IT%20Employment%20report.pdf>

Michaels, A. (2009)

<http://www.telegraph.co.uk/news/worldnews/europe/italy/6417105/Italian-women-say-ciao-to-the-showgirl-image.html>.

Miller, P. (2004) Demographic And Gender Regimes: The Case of Italians and Ethnic Traditions. *Journal of Population Research*. Vol.21 (2). Pp.199-222.

Morgan, G. & Smircich, L. (1980) The Case for Qualitative Research. *Academy of Management Review*. Vol.5(4). Pp.491-500.

Morris, J. (ed). (1989) *Able Lives. Women's Experience of Paralysis*. The Women's Press. London: Chapter 8. *Being a Mother*. Pp. 125-139.

Morris, J. (1992) Personal and Political: a feminist perspective on researching physical disability. *Disability, Handicap & Society*. Vol.7(2). Pp.157-166.

Morris, J. (1993a) Feminism and Disability. *Feminist Review*. Vol. 43. Pp.57-70.

Morris, J. (1993b) Gender and Disability. In Swain, J.; Finkelstein, V.; French, S. and Oliver, M. (eds). (1993) *Disabling Barriers – Enabling Environments*. London. Sage in association with The Open University.

Morris, J. (1998) Feminism, gender and disability. (*Text of a paper presented at a seminar in Sydney, Australia: February 1998*). Accessed from <http://disability-studies.leeds.ac.uk/files/archiveuk/morris-gender-and-disability.pdf> on 24.11.2012.

Morris, J. (2001) Impairment and disability: constructing an ethics of care which promotes human rights. (*Penultimate draft of article published in Hypatia, Vol. 16, No. 4, Fall 2001*).

Accessed from <http://www.leeds.ac.uk/disability->

[studies/archiveuk/morris/constructing%20an%20ethics%20of%20care%20which%20promotes%20human%20rights.pdf](http://www.leeds.ac.uk/disability-studies/archiveuk/morris/constructing%20an%20ethics%20of%20care%20which%20promotes%20human%20rights.pdf) on 24.11.2012.

Morris, J. (2011) Rethinking Disability Policy. Accessed from

<http://www.jrf.org.uk/publications/rethinking-disability-policy> on 24.11.2012.

MS Society (2010) Accessed from www.mssociety.org.uk.

Naldini, M. & Saraceno, C. (2008) Social and Family Policies in Italy: Not Totally Frozen but Far from Structural Reforms. *Social Policy and Administration*. Vol.42(7). Pp.733–48.

Natali, D. (2006) 'From Italy to Europe': a review of recent Italian literature on social policy. *Journal of European Social Policy* Vol.16. Pp.287-292.

National MS Society last accessed from <http://www.nationalmssociety.org/index.aspx> on 01/09/13.

Newman, T. (2002) 'Young Carers' and Disabled Parents: time for a change of direction? *Disability & Society*. Vol. 17(6). Pp.613-625.

Norlyk, A. & Harder, I. (2010) What Makes a Phenomenological Study Phenomenological? An Analysis of Peer-Reviewed Empirical Nursing Studies. *Qualitative Health Research*. Vol.20(3). Pp.420–431.

O'Connor, F.B. & Drury, B.S. (1999) *The Female Face in Patriarchy. Oppression as Culture*. Michigan State University Press.

Oliver, M. (1996) Chapter 3: *Defining Impairment and Disability: Issues at Stake*. In *Exploring the Divide*. Barnes, C. & Mercer, G. (eds). The Disability Press. Leeds.

Oliver, M. (2002) *Paper from the 1st Annual Disability Research Seminar*. Using Emancipatory Methodologies in Disability Research.

Olsen, R. & Clarke, H. (2003) *Parenting and Disability. Disabled parent's experiences of raising children*. The Policy Press. Bristol, U.K.

Onwuegbuzie, A.; Leech, N.L. & Collins, K.M.T. (2010) Innovative Data Collection Strategies in Qualitative Research. *The Qualitative Report*. Vol.15(3). Pp.696-726.

Open University library

<http://library.open.ac.uk/libezproxy.open.ac.uk/search/onestophelp.pdf>. Last accessed on 19.08.2013.

- Parker White, C.; Mendoza, J.; White, M.B. & Bond, C. (2009a) Chronically ill mothers experiencing pain: relational coping strategies used while parenting young children. *Chronic Illness*. Vol.5. Pp.33-45.
- Parker White, C.; White, M.B. & Fox, M.A. (2009b) Maternal Fatigue and Its Relationship to the Caregiving Environment. *Families, Systems & Health*. Vol.27(4). Pp.325-345.
- Patton, M.Q. (2002) *Qualitative research and evaluation methods 3rd edition*. Sage Publications, California in Smith, J.; Bekker, H. & Cheater, F. (2011). Theoretical versus pragmatic design in qualitative research. *Nurse Researcher*. Vol.18(2). Pp.39-51.
- Payne, D. & McPherson, K.M. (2010) Becoming mothers. Multiple Sclerosis and motherhood: A qualitative study. *Disability and Rehabilitation*. Vol. 32(8). Pp.629-638.
- Pianigiani, G. (2011) Sex Scandals in Italy Fuel Discontent of Women. New York Times. Accessed from <http://www.nytimes.com/2011/02/03/world/europe/03italy.html>
- Potter, S. (2006) *Doing Postgraduate Research*. Sage. London.
- Priestley, M. (2007) In search of European disability policy: Between national and global. *Revue europeene de recherché sur le handicap*. Vol.1. Pp.61-74.
- Prilleltensky, O. (2003) A Ramp to Motherhood: The Experiences of Mothers with Physical Disabilities. *Sexuality & Disability*. Vol.21(1). Pp.21-47.

Prilleltensky, O. (2004) My child is not my carer: mothers with physical disabilities and the well being of children. *Disability & Society*. Vol.19(3). Pp.209-223.

Pringle, J.; Hendry, C.; and McLafferty, E. (2011a) Phenomenological approaches: challenges and choices. *Nurse Researcher*. Vol.18(2).Pp.7-18.

Pringle, J.; Drummond, J.; McLafferty, E. and Hendry, C. (2011b) Interpretative phenomenological analysis: a discussion and critique. *Nurse Researcher*. Vol.18(3).Pp.20-24.

Prunty, M.; Sharpe, L.; Butow, P. & Fulcher, G. (2008a) The motherhood choice: Themes arising in the decision making process for women with multiple sclerosis. *Multiple Sclerosis*. Vol. 14. Pp. 701-704.

Prunty, M.; Sharpe, L.; Butow, P. & Fulcher, G. (2008b) The motherhood choice: A decision aid for women with multiple sclerosis. *Patient Education and Counselling*. Vol.71(1). Pp.108-115.

Radcliffe, V. (2008) "Being Brave": Disabled Women and Motherhood. Accessed from the Disability Archive <http://www.leeds.ac.uk/disability-studies/archiveuk/radcliffe/Dissertation%20Victoria%20Radcliffe.pdf> on 26th November 2012.

Raval, H. & Smith, J.A. (2003) Therapists' experiences of working with language interpreters. *International Journal of Mental Health*. Vol.32.Pp.6-31.

Regmi, K.; Naidoo, J. & Pilkington, P. (2010) Understanding the Processes of Translation and Transliteration in Qualitative Research. *International Journal of Qualitative Methods*. Vol.9(1). Pp.16-26.

Reid, K.; Flowers, P. & Larkin, M. (2005) Exploring lived experience. *The Psychologist*. Vol.18(1). Pp.20–23.

Reid, D.; Angus, J.; McKeever, P. & Miller, K.L. (2003) Home Is Where Their Wheels Are: Experiences of Women Wheelchair Users. *American Journal of Occupational Therapy*. Vol.57. Pp.186-195.

Reissman, C. (1993) Narrative Analysis. *Qualitative Research Methods*. Vol.30. Pp.1-78. In Temple, B. (2005) Nice and Tidy: Translation and Representation. *Sociological Research Online*. Vol.10(2). Accessed from <http://www.socresonline.org.uk/10/2/temple.html> on 10.08.2011.

Reynolds, F. & Prior, S. (2003) “Sticking jewels in your life”: Exploring women’s strategies for negotiating an acceptable quality of life with multiple sclerosis. *Qualitative Health Research*. Vol.13. Pp.1225–1251.

Reynolds, F.; Vivat, B. & Prior, S. (2008) Women’s experiences of increasing subjective well-being in CFS/ME through leisure based arts and crafts activities: A qualitative study. *Disability and Rehabilitation*. Vol.30. Pp.1279–1288.

- Riessman, C.K. (1993) Narrative Analysis. *Qualitative Research Methods*. Series 30. Newbury Park, Sage.
- Riley, L.D. & Bowen, C. (2005) The Sandwich Generation: Challenges and Coping Strategies of Multigenerational Families. *The Family Journal*. Vol.13(1). Pp.52-58.
- Ritsher, J.B.; Otilingam, P.G. & Grajales, M. (2003) Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry Research*. Vol. 121(1). Pp. 31–49.
- Rizzi, E. and Kertzer, D. (2010) Intergenerational downward ties and fertility intentions in Italy. *Extended abstract European Population Conference, Vienna, Austria*. Accessed from <http://epc2010.princeton.edu/papers/100917> on 29.04.2013.
- Rousso, H. (2013) *Don't Call Me Inspirational A Disabled Feminist Talks Back* Philadelphia, USA. Temple University Press.
- Ruggiero, C. (2012) Forecasting in the Politics of Spectacle, From Berlusconi to Grillo: The Narrative of Impolite Politics. *Bulletin of Italian Politics*. Vol.4(2). Pp.305-322.
- Rutkauskiene, L. (2010) Social policy in the European Union: Variety and Challenges. *Public Administration*. Vol.1/2(25/26). Pp.26-33.
- Saraceno, C. (1994) The Ambivalent Familism of the Italian Welfare State. *Social Policy*. Vol.1(1).Pp.60-82.

Saraceno, C. (2004) The Italian family from the 1960s to the present. *Modern Italy*. Vol.9(1). In Crowhurst, I. & Bertone, C. (2012). Introduction: the politics of sexuality in contemporary Italy. *Modern Italy*. Vol.17(4). Pp.413-418.

Saraceno, C. (2010) Women and Gender Studies in Italy : Lack of Institutionalization or a Different Kind of Institutionalization? *European Journal of Women's Studies*. Vol. 17(3.) Pp. 269-274.

Saraceno, C. & Terracina, S. (2005) Social Quality in Italy. *European Journal of Social Quality*. Vol.5(1/2). Pp176-185.

Sarti, R. (2010) Who cares for me? Grandparents, nannies and babysitters caring for children in contemporary Italy. *Paedagogica Historica*. Vol. 46(6). Pp.789–802.

Seidman, I.E. (1991) Interviewing As Qualitative Research. *A Guide for Researchers in Education and the Social Sciences*. New York. Teachers College Press.

Shakespeare, T. & Watson, N. (2001) The Social Model of Disability: An Outdated Ideology? Exploring Theories and Expanding Methodologies. *Research in Social Science and Disability*. Vol.2. Pp. 9-28.

Shaw, R.L. (2001) Why use interpretative phenomenological analysis in Health Psychology? *Health Psychology Update*. Vol.10(4). Pp.48-52.

Smeltzer, S.C.(1994) Concerns of pregnant women with multiple sclerosis. *Qualitative Health Research*. Vol.4. Pp.480-502.

Smeltzer, S.C.(2002) Reproductive decision making in women with multiple sclerosis. *Journal of Neuroscience Nursing*. Vol.34. Pp.145–157.

Smith, J.A. (1996) Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*. Vol.11. Pp.261–271.

Smith, J.A. (1999) Towards a relational self: Social engagement during pregnancy and psychological preparation for motherhood. *British Journal of Social Psychology*. Vol.38. Pp. 409–426.

Smith, J.A. (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*. Vol.1. Pp.39–54.

Smith, J.A. (2007) Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-being*. Vol.2. Pp.3–11.

Smith, J. (2010) Interpretative Phenomenological Analysis. A Reply to Amedeo Giorgi. *Existential Analysis*. Vol.21(2).Pp.186-192.

Smith, J.A. & Eatough, V. (2006) Interpretative phenomenological analysis. In: Breakwell, G.M.; Hammond, S.; Fife-Schaw, C. & Smith, J.A. (eds). *Research Methods in Psychology*. Pp.322–341.

Smith, J.A. & Osborn, M. (2008) Interpretative phenomenological analysis. In Smith JA (ed), *Qualitative Psychology: A Practical Guide to Research Methods*. 2nd ed. Pp.53–80. London, Sage.

Smith, J.A.; Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. London. Sage.

Smith, J.; Bekker, H. & Cheater, F. (2011) Theoretical versus pragmatic design in qualitative research. *Nurse Researcher*. Vol.18(2). Pp.39-51.

Spencer, S. (2008) Equality and Human Rights Commission: A Decade in the Making. *The Political Quarterly*. Vol.79 (1). Pp.6-16.

Squires, A. (2008) Language barriers and qualitative nursing research: methodological considerations. *International Nursing Review*. Vol.55. Pp.265-273.

- Standing, M. (2009) A new critical framework for applying hermeneutic phenomenology. *Nurse Researcher*. Vol.16(4). Pp.20-30.
- Starks, H. & Trinidad, S.B. (2007) Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and Grounded Theory. *Qualitative Health Research*. Vol. 17(10). Pp.1372-1380.
- Starks, H.; Morris, M.A.; Yorkston, K.M.; Gray, R.F. & Johnson, K.L. (2010) Being in- or out-of-sync: couples' adaptation to change in multiple sclerosis. *Disability and Rehabilitation*. Vol.32(3). Pp.196-206.
- Stone, S.D. (2005) Reactions to invisible disability: The experiences of young women survivors of hemorrhagic stroke. *Disability and Rehabilitation*. Vol. 27(6). Pp. 293-304.
- Storr, A. (2007) Motherhood, Parenting and Women With Disabilities: A Literature Review. Women with Disabilities Australia. Accessed from <http://www.wwda.org.au/motherhdlitrev1.htm> on 12/07/2011.
- Sundström, E. (1999) Should mothers work? Age and attitudes in Germany, Italy and Sweden. *International Journal of Social Welfare*. Vol.8. Pp.193-205.
- Taft, T.H.; Ballou, S. & Keefer, L. (2013) A preliminary evaluation of internalized stigma and stigma resistance in inflammatory bowel disease. *Journal of Health Psychology*. Vol.18(4). Pp.451-460.

Tarleton, B. & Ward, L. (2007) "Parenting With Support": The Views and Experiences of Parents With Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*. Vol.4(3). Pp. 194–202.

Temple, B. (2002) Crossed Wires: Interpreters, Translators, and Bilingual Workers in Cross-Language Research. *Qualitative Health Research*. Vol.12(6). Pp.844-854.

Temple, B. (2005) Nice and Tidy: Translation and Representation. *Sociological Research Online*. Vol.10(2). Accessed from <http://www.socresonline.org.uk/10/2/temple.html> on 10.08.2011.

Temple, B. (2006) Representation across languages: biographical sociology meets translation and interpretation studies. *Qualitative Sociology Review*. Vol.2(1). Pp.7-21.

Temple, B. (2008) Narrative analysis of written texts: reflexivity in cross language research. *Qualitative Research*. Vol.8(3). Pp.355-365.

Temple, B., & Edwards, R. (2002) Interpreters/translators and cross-language research: Reflexivity and border crossings. *International Journal of Qualitative Methods*. Vol.1(2). Pp.1-22.

Temple, B. & Young, A. (2004) Qualitative research and translation dilemmas. *Qualitative Research*. Vol.4(2). Pp.161-178.

The Care Quality Commission. Accessed from

<http://www.cqc.org.uk/guidanceforprofessionals/adultsocialcare/legislation.cfm>.

The Guardian (2011) Accessed from

<http://www.guardian.co.uk/commentisfree/2011/feb/15/berlusconi-italy-women-sexism>

Thomas, C. (1997) The baby and the bath water: Disabled women and motherhood in social context. *Sociology of Health & Illness*. Vol.19(5). Pp.622-643.

Thorne, S. (2000) Data Analysis in qualitative research. *Evidence-Based Nursing*. Vol.3(3).Pp.68-70.

Timmins, F. & McCabe, C. (2005) How to conduct an effective literature search. *Nursing Standard*. Vol.20 (11). Pp.41-47.

Timotijevic, L. & Breakwell, G.M. (2000) Migration and threat to identity. *Journal of Community & Applied Social Psychology*. Vol.10(5). Pp.355-372.

Todres, L. & Wheeler, S. (2001) The complementarity of phenomenology, hermeneutics and existentialism as a philosophical perspective for nursing research. *International Journal of Nursing Studies*. Vol.38.Pp.1-8.

Tomassini, C.; Kalogirou, S.; Grundy, E.; Fokkema, T.; Martikainen, P.; Broese van Groenou, M. & Karisto, A. (2004) Contacts between elderly parents and their children in four

European countries: current patterns and future prospects. *European Journal of Ageing*. Vol.1. Pp.54–63.

Tomassini, C.; Glaser, K. & Stuchbury, R. (2007) Family Disruption and Support in Later Life: A Comparative Study Between the United Kingdom and Italy. *Journal of Social Issues*. Vol.63(4).Pp.845-863.

Traps, Y. (2009) Representing the Translator: Making Sense of Translation in Cross-Language Qualitative Research. A review of Bogusia Temple's Recent Investigations in Research and Translation. *Graduate Journal of Social Science*. Vol.6(3). Pp.142-147.

Turpin, M.; Leech, C & Hackenberg, L. (2008). Living with Parental Multiple Sclerosis: Children's Experiences and Clinical Implications. *Canadian Journal of Occupational Therapy*. Vol.75(3). Pp.149-156.

Twinn, S. (1997) An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. *Journal of Advanced Nursing*. Vol.26. Pp.418-423.

Twork, S.; Wirtz, M.; Schipper, S.; Klewer, J.; Bergmann, A. & Kugler, J. (2007) Chronical illness and maternity: life conditions, quality of life and coping in women with multiple sclerosis. *Quality of Life Research*. Vol.16. Pp.1587-1594.

Uccelli, M.M.; Battaglia, M.A.; Zagami, P. & Solaro, C. (2002) The interdisciplinary approach to the treatment of multiple sclerosis patients in Italy: an aspiration or a reality? *Multiple Sclerosis*. Vol.8. Pp.36-39.

Uccelli, M.M.; Specchia, C.; Battaglia, M. A. & Miller, D. M. (2009) Factors that influence the employment status of people with multiple sclerosis: a multi-national study. *Journal of Neurology*. Vol. 256(12). Pp.1989-1996.

United Nations Convention on the Rights of Persons with Disabilities. Accessed from www.un.org/disabilities on 15.04.2011.

Verbruge, L.M. & Yang, L.S. (2002) Aging with disability, and disability with aging. *Journal of Disability Policy Studies*. Vol.12. Pp. 253-267.

Waldschmidt, A. (2009) Disability policy of the European Union: The supranational level. *European Journal of Disability*. Vol. 3. Pp. 8-23.

Wallin, A.M. & Ahlström G. (2006) Cross-cultural interview studies using interpreters: systematic literature review. *Journal of Advanced Nursing*. Vol.55(6). Pp.723-35.

Wallin, M.T.; Wilken, J.A.; Turner, A.P.; Williams, R.M. & Kane, R. (2006) Depression and multiple sclerosis: Review of a lethal combination. *Journal of Rehabilitation Research & Development*. Vol. 43(1). Pp.45-62.

Wates, M. (1997) *Disabled parents: Dispelling the myths*. Cambridge. National Childbirth Trust Publishing. In Prilleltensky, O. (2003) *A Ramp to Motherhood: The Experiences of Mothers with Physical Disabilities*. *Sexuality & Disability*. Vol.21 (1). Pp.21-47.

Wates, M. & Jade, R. (1999) *Bigger than the sky, disabled women on parenting*. Women's Press. London.

Watson, N. (2012) How can disability theory help our understanding of the lives of disabled children. Accessed from http://www.strath.ac.uk/media/faculties/hass/appliedsocialsciences/socialwork/esrcseminar/Disability_theory_Watson_N.pdf on 01/09/2013

Watson, N.; McKie, L.; Hughes, B.; Hopkins, D. & Gregory, S. (2004) (Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model. *Sociology*. Vol.38(2). Pp.331-350.

Whaley, D.E. (2001) Feminist Methods and Methodologies in Sport and Exercise Psychology: Issues of Identity and Difference. *The Sport Psychologist*. Vol.15. Pp.419-430.

Wineman, N.M (1990) Adaptation to Multiple Sclerosis: The Role of Social Support, Functional Disability, and Perceived Uncertainty. *Nursing Research*. Vol. 39(5).

Wilcock, A.A. (1999) Reflections on doing, being and becoming. *Australian Occupational Therapy Journal*. Vol.46.Pp1-11.

Wilding, C. & Whiteford, G. (2005) Phenomenological research: an exploration of conceptual, theoretical and practical issues. *OTJR. Occupation, Participation and Health*. Vol. 25(3).Pp.98-104.

Wilding, C. (2011) Phenomenological research: an exploration of conceptual, theoretical and practical issues. (pre-publication version) *OTJR*. 25(3).

Yardley, L. (2000) Dilemmas in Qualitative Health Research. *Psychology and Health*. Vol.15.Pp.215-228.

Yeung, W.J.; Sandberg, J.F.; Davis-Kean, P.E. & Hofferth, S.L. (2001) Children's Time With Fathers in Intact Families. *Journal of Marriage and Family*. Vol.63. Pp.136-154.

Zontini, E. (2006) Italian Families and Social Capital. *Community, Work and Family*. Vol.9(3). Pp.325-345.

Appendix 1.

The Faculty of Health and Social Care, The Open University

An investigation into the experience of being a disabled mother.

Agreement to Participate

I, (print name)
agree to take part in this research project.

I have had the aims of the research project explained to me.

I understand that I can change my mind about participating at any point by simply saying so.

I understand that my confidentiality will be protected as specified in the participants' information sheet.

I agree that the information that I provide can be used for educational or research purposes, including publication.

I understand that if I have any concerns or difficulties I can contact:

Michele Messmer Uccelli

Sede Nazionale AISM Onlus

Via Operai 40, 16149 Genova

Tel.: 010/2713233 email: michele@aism.it

Signed:

Date:

Appendix 2:

Participants' Information Sheet:

Why have I been sent this letter?

You are being invited to take part in a study that will be exploring the experience of being a mother with a disability. You have been identified from the AISM database as being a woman who has MS, who has responsibility for at least one child who is under 18 years of age, who is still living at home.

Who is doing the research and why?

The researcher (Catherine Wilson) is a PhD student at the Open University in England. As Catherine does not speak Italian as her first language, a therapist from AISM will also be helping her with the research. The overall aim of the project is to find out about your experience of being a mother with Multiple Sclerosis, to see how it impacts on your day to day life with your child(ren). Some of the things the researcher is interested in hearing about are:

- Does living with MS effect you as a mother and impact on you participating in your child(ren)'s life?
- Since you have had MS, who has supported you in your role as a mother? How effective do you think this support is? How did you find out about what support was available?
- Do the symptoms of your MS effect you in other "mothering roles" such as tasks around your home, assisting with your children's basic care needs, helping them with dressing, feeding, bathing etc. If you need help in these areas, do you get the help you need?
- Are there other things outside your home that effect how you carry out your role as a mother, such as barriers in the environment and accessibility to places your child goes to, or attitudes of other people towards you?

What information will I need to give?

People taking part in the research will be asked about their past and present experience of being a mother who has Multiple Sclerosis. Some people will also be asked to share their thoughts about their future role as a mother too. You will be asked about whether you have any support with any tasks related to being a mother, on account of your disability. This is to find out who gives what kind of support and how useful and easy to obtain this support is. You will be asked about activities you participate in with your child(ren) and whether the symptoms of your MS impacts on these.

A number of mothers are being asked to share their experiences and the information will be analysed to see if there are similarities in what people's experiences are. This will help to identify women's views of what services would best support them in their role as mothers and any barriers that impact on them fully participating in their child(ren)'s life.

How will this information be gained?

If you agree to participate in the project, you will be interviewed about your experience. The interview will take place in your own home and an interviewer and an observer will visit you to conduct the interview. The interviews will be audio taped. The observer will be the research student (Catherine Willson) and the interviewer will be a therapist from AISM. The interviewer will have some guideline questions to ask you, but you will be sharing your experience. The interviews will start in August 2011 and run through to June 2012. You may be asked to do two interviews. You can give as much or as little information as you feel comfortable in sharing, but the interviews should not last more than two hours.

Interviews will be recorded and analysed to compare information participants give. You will therefore be asked to agree to the information you share being included in the research analysis and findings. A short summary of the interview will be sent to you afterwards and you will be asked to read through it and let the researcher know if you agree that it summarises what you have said.

Who will see this information?

Each person taking part in the research will sign a personal confidentiality agreement. Your individual information will only be shared between the OU researcher and the interviewer. The taped interviews will be sent to an external translator, who will also sign a confidentiality agreement. Your personal information will not be passed on to any other third party.

Confidentiality.

The information you give to the interviewer and observer during the interviews will be made anonymous. That means that any features that would identify you individually will be removed when the data is analysed.

If any data gathered is used for publication in academic journals and other media, this information will also be anonymised, i.e. your name and identifying features will be removed so that, for example, direct quotes cannot be identified. However, if you wish to have your contribution as an individual recognised, you can ask to be named as a participant in the final report.

We have a strategy in place (see below) to deal with the storage and anonymisation of personal information that you give us for this research project. We are not aware of any potential risks from being involved in the research.

Ethics.

This research has the approval of the Open University's Human Materials and Participants Ethics Committee, which has examined the research proposal and documentation. The AISM scientific committee has also approved the research study. The research will also comply with the Code of Ethics and Professional Conduct (College of Occupational Therapists, 2010).

How will this information be kept safe?

The Open University has a strict data protection policy. Digital data stored on computers will be password protected and exchanged between the researcher and transcriber using an encrypted format. Paper copies of information will be stored in a locked cupboard at the AISM or the researcher's office.

Can I find out the results of the research?

Everyone who participates in the research will be given a summary document of the findings of the research. A full copy of the findings will be available on request.

What if I change my mind?

If you decide to participate and then later change your mind, you have the right to withdraw from the research at any point and this will not affect your rights or your involvement with any service you receive from AISM. If you do withdraw we will discuss with you whether you want the information you have given us to date to be included in the research analysis on the basis of confidentiality described below. If you prefer to have your data removed it will be destroyed.

If you have any questions.

If now or during the course of the research you want to raise any **questions or comments** about the research please contact:

Michele Messmer Uccelli
Sede Nazionale AISM Onlus
Via Operai 40, 16149 Genova
Tel.: 010/2713233 email: michele@aism.it

If you want to make a **complaint or raise concerns** about how the research is being carried out, you can contact:

Michele Messmer Uccelli
Sede Nazionale AISM Onlus
Via Operai 40, 16149 Genova
Tel.: 010/2713233 email: michele@aism.it

Or:

Dr Sarah Earle,
Associate Dean (Research)
Faculty of Health and Social Care
The Open University
Walton Hall
Milton Keynes
MK7 6AA
s.earle@open.ac.uk

Tel: Katy Perry (PA to Dr Earle) 00 44 908 332964

Appendix 3:

From Dr Duncan Banks
Chair, The Open University Human Research Ethics Committee

Email d.banks@open.ac.uk

Extension 59198

To Catherine Willson, Health and Social Care.

Subject *'An investigation into the experience of being a disabled mother.'*

Ref HREC/2011/#1002/1

Red form n/a

Submitted 15 July 2011

Date 21 July 2011

Memorandum

This memorandum is to confirm that the research protocol for the above-named research project, as submitted for ethics review, **is approved** by the Open University Human Research Ethics Committee. Before you start your research you will need to address the following points identified by the reviewers;

1. The information sheet says that the interviews will be audio recorded, whereas the ethics application implies that there will be audio-visual recorded. Is the recording of the visual aspects going to use technology or do you plan to take field notes?
2. To the best of your knowledge does the Italian 'version' of the Data Protection Act (if there is one) place restrictions on the AISM's ability to randomly ringing members to see if they wish to participate?
3. Three reviewers shared their concerns about the characterisation of MS as a disability and then to extrapolate the results to claim that these are relevant to the wider field of disability. Would it not be easier to leave the word 'disability' out of the application and replace it, where possible, with 'MS'?

4. How do you intend to deal with the sometimes unrealistic optimism which is frequently symptomatic of MS sufferers to ensure that the data gathered is a fair and reasonable reflection (c.f. Fournier, M, de Ridder, D and Brensing, J. (1999) 'Optimism and Adaptation in Multiple Sclerosis: What does Optimism mean' *The Journal of Behavioural Medicine* 22(4) pp. 303-326)?

5. Do you intend to contextualise the difficulties that mothers with MS may have within the cyclical nature of acute episodes and remissions?

Please make sure you address the above points and reply to Research-REC-Review@open.ac.uk. We will endeavour to respond as quickly as possible so that your research is not delayed in any way.

At the conclusion of your project, by the date that you stated in your application, the Committee would like to receive a summary report on the progress of this project, any ethical issues that have arisen and how they have been dealt with.

Regards,

Duncan Banks
Chair OU HREC

The Open University is incorporated by Royal Charter (RC 000391), an exempt charity in England & Wales and a charity registered in Scotland (SC 038302).

Appendix 4:

Responses to question posed by Ethics panel – July 2011.

1. The information sheet says that the interviews will be audio recorded, whereas the ethics application implies that there will be audio-visual recorded. Is the recording of the visual aspects going to use technology or do you plan to take field notes?

The interviews are going to be audio recorded, not audio visually recorded, but the visual aspects will be recorded by the use of field notes. Apologies for the lack of clarify of this in the ethics application.

2. To the best of your knowledge does the Italian 'version' of the Data Protection Act (if there is one) place restrictions on the AISM's ability to randomly ringing members to see if they wish to participate?

I am trying to ascertain the specifics of any data protection protocols in Italy and will ensure that I comply with any stated requirements. However, the administrator who will be contacting potential participants by phone will have full access to the database in any event, as it will be someone who accesses the database on a regular basis to input data, make appointments etc. I will ensure that any records that they keep of who they have contacted and their responses will be kept in a separate electronic file which will be password protected and deleted when the appropriate number of participants have signed consent forms and agreed to participate in the study.

3. Three reviewers shared their concerns about the characterisation of MS as a disability and then to extrapolate the results to claim that these are relevant to the wider field of disability. Would it not be easier to leave the word 'disability' out of the application and replace it, where possible, with 'MS'?

Women with MS serve as an exemplar to enable me to investigate the experiences of "disabled" women who are mothers. The purpose of my study is to investigate the experiences of mothers who are medically defined as being "disabled", whether or not they self-identify as being disabled women. The same could equally apply to other groups, such as women with chronic fatigue syndrome, rheumatoid arthritis, or even dyslexia. All of these groups come within the medical definition of being disabled; on account of them having long term impairments which impact on their daily lives, but may not necessarily represent women who self-identify as being disabled. The reason I have chosen to interview women at various stages of their MS is to investigate experiences of women who have different levels of impairment, which may or may not impact on their experiences of being disabled mothers. My study is more concerned with how the women feel about their experiences of having impairments impacts on them as mothers and how support that they receive empowers them, or not, to maintain the role of mother in the way that they choose.

4. How do you intend to deal with the sometimes unrealistic optimism which is frequently symptomatic of MS suffers to ensure that the data gathered is a fair and reasonable reflection (c.f. Fournier, M, de Ridder, D and Brensing, J. (1999) 'Optimism and Adaptation in Multiple Sclerosis: What does Optimism mean' The Journal of Behavioural Medicine 22(4) pp. 303-326)?

Thank you for bringing this interesting article to my attention. What struck me most was the question the authors posed about whether or not the model of optimism they proposed was independent of the circumstances. In undertaking in-depth interviews, it is my intention to thoroughly consider the circumstances of my participants, which may or may not impact on their optimism. I note that Fournier et al found that their participants

were not significantly unrealistically optimistic with regards to positive events, but were significantly unrealistically optimistic with regard to negative events. Through using a phenomenological approach to my analysis, I intend to report how my participants, within their own life context, make sense of the impact of their impairment on their role as mothers, which may involve aspects of their optimistic or pessimistic approach to managing the impact of their MS. However, I am also aware of the perhaps more frequently recognised link between MS and depression, for example Wallin et al's (2006) review of depression and MS which cites 137 references, many of which concern depression in people with MS. The levels of optimism, coping strategies and adjustment that my participants experience will be represented as part of their individual experience, rather than seeking to be representative of disabled women's experiences more generally.

5. Do you intend to contextualise the difficulties that mothers with MS may have within the cyclical nature of acute episodes and remissions?

Yes. This will be further explored in the second interviews, in considering futures and how women feel about the future for them as mothers and the impact of their MS. I also intend to gain support from my supervisory team and draw on their experience to assist me with this. For example one of my supervisors is a registered nurse with a PhD who has worked in a neuro medical setting supporting patients with Multiple Sclerosis and has an awareness and experience of supporting people through these experiences.

Catherine Willson 28.07.2011

>> On Fri, Jul 29, 2011 at 7:15 PM, Duncan Banks <D.Banks@open.ac.uk> wrote

>>> Dear Catherine,

>>>

>>> Thank you for your email. I think that your responses are more than

>>> adequate on each of the review questions and that you should start your

>>> research as soon as is practical.

>>>

>>> Best wishes,

>>>

>>> Duncan

Appendix 5:

General introductions and thanks for agreeing to participate.

The aim of this study is to find out about your experiences of being a mother who has MS. It is to find out about your experiences and what they mean to you. As you will know from the information sheet, the information you give is going to be tape recorded, then typed up and then translated into English, so that I (Catherine) will be able to look at it and compare it to what other mothers say about their experiences.

The information you give will be confidential, that means it will be kept safe and your name won't be used in any information that it written up about the study. You can change your mind about participating in the study at any time. You will receive a summary document about the findings at the end of the study, but a full copy will also be available if you would like one. Before we begin, is there anything you wanted to ask about the study?

1. Can you start by telling us a little bit about yourself; tell us a little about your life?
Prompts: Are you and your family from (Genoa)? Did you go to school in Genoa? Have you lived in this area long? Do you have family in this area or have they moved away? Do you work? Did you work before you had children? What did/do you do? Did/do you enjoy working? Did you finish work when you had your children? What do you like and dislike? What do you enjoy doing?
2. Could you tell us a little bit around your family and your children? Such as how many children you have, how old they are? *Prompts: do they go to a local school? Or are they involved in out of school activities?*
3. Did you have your children before or after you were diagnosed with MS? *Prompts: If no MS when had children: so when you had (first child's name) did you have any symptoms of MS? OR If had children when already diagnosed: how long was it after your diagnosis that you had (child's name)?*
4. What does being a mother mean to you? (if struggling "if I asked you to give me an adjective to describe your role, what would you use?)
5. Have things changed in relation to your mothering, depending on the ages and needs of your children or your MS symptoms?
6. Since the onset of your MS, have you had any help from your family in caring for your children? *Prompt: does your husband or your mother help you in looking after the children?* Could you tell us about that help? (If answer is no "why do you not have any help?)
7. How do you feel about this help?

8. How do you feel (or would you feel if answer is "no") about asking for help from your family?
9. Have you had any help from other people: friends, the MS society for example?
Prompts: if they have said above that mother/husband helps, say "what about other members of your family" or "do the MS society provide helpers for you?" "Do your friends offer help to you?" what kind of help?
10. If yes - Could you tell us about that help and how you feel about it?

How did you find out about this help and how did you feel about asking for it?
OR If no - If you needed help, how would you find out about what is available and how would you feel about asking for help?
11. Is there any help that you feel you need now, or might need in the future or any help that you could have done with in the past that wasn't available? *Prompts: do you think you might need help in taking the children to activities, do you think you might need more help from the MS society for example? Or is there any equipment or adaptations to your house that would be helpful?*
12. Tell me about how you feel about being a mother with MS?
13. Do you think having MS has impacted on your relationships with your children?
14. How do you feel those around you, your family, friends, the community for example respond to you as a mother with MS?
15. Are there other things in relation to your role as a mother that are affected by having MS? *Prompts: going to community activities with your children, driving your children to school or to friends' houses for example?*
16. What are the best and most challenging aspects of being a mother?
17. If you could give one piece of advice to a woman with MS who was thinking about having a child, what would that be?
18. Do you find that you live in the present, or do you think much about the past and the future?
19. That is everything we wanted to ask you, but is there anything else about being a mother that you would like to share with us?

Thank you very much for your time and it was lovely to meet you. We may want to come back and ask you some further questions – is that ok with you?

Appendix 6:

Follow up Questions:

The influence of medics in decision making (for Alessandra, Sonia and Silvia)

- What advice were you given about becoming pregnant and the impact it could have had on your MS?
- Was this advice useful?
- Did this advice influence your decision at all and if so, how?
- What level was your MS at and how was it impacting on your function when you became pregnant?

Differences in responses from teenagers and younger children (for Elisa, Patrizia, Maria & Silvia)

- Dealing with adolescents is challenging for any parent. Do you think it is more of a challenge for women with MS and if so, in what ways? Or do you think the challenges are the same?
- What (if any) issues do you think need to be addressed?
- What (if any) support would help with this?

Attitudes of society in responding to disabled people in general (for all)

- How do you think Italian society reacts to people who are disabled?
- Do you identify yourself as a disabled person? Why?
- Do you think people who use wheelchairs are treated differently to people who are disabled in other ways?
- Do you think the government has a role to play in how society provides for disabled people?
- What about the church? Do you think the church plays any role in influencing how society responds to disabled people?
- Do you think there are areas in which change is needed? If so, what are they?
- Do you think things will change? If so, how? If not, why?
- Do you think that the fact that your children have grown up with MS will impact on how they react to other people who are disabled?

- Do you think the next generation will have a different view about disabled people?

Hidden impairments - both how people hide them and whether this is related to how society responds to disabled people (for all)

- Do you have any symptoms from your MS that are invisible, ie that other people don't see? If so, do you talk about how these symptoms affect you with other people, or do you keep these to yourself?
- Some people we have interviewed have talked about how the perception is that MS is about having motor problems and being in a wheelchair. Do you think that the symptoms that other people can't see, like fatigue and visual problems for examples, are more of a disability than the motor problems?
- Do you feel that people (wider society) (would) react differently to you as a woman in a wheelchair/with a walking stick than they do if your MS affected you differently in ways that other people couldn't see, for example fatigue, pain, problems with your memory?

Appendix 7:

Photograph to show grouping of sub-themes.

